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SCHIZOPHRENIA: THE PLIGHT AND THE PROMISE

HEARING

BEFORE A

SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS UNITED STATES SENATE

NINETY-NINTH CONGRESS

SECOND SESSION

SPECIAL HEARING

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SCHIZOPHRENIA: THE PLIGHT AND THE PROMISE

THURSDAY, NOVEMBER 20, 1986

U.S. SENATE,
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES,
COMMITTEE ON APPROPRIATIONS,
Washington, DC.

The subcommittee met at 9:30 a.m., in room SD–116, Dirksen Senate Office Building, Hon. Lowell P. Weicker, Jr. (chairman) presiding.

Present: Senators Weicker, Domenici, and Proxmire.

Also present: Senator D'Amato.

NONDEPARTMENTAL WITNESSES

OPENING REMARKS OF SENATOR WEICKER

Senator WEICKER. The subcommittee will come to order.

Good morning. I won't take a long time with an opening statement this morning, but I do want to provide some context for the information the committee will receive this morning.

About 19 months ago, my staff concluded a 6-month investigation of State facilities for the mentally disabled. Through that investigation and in subsequent hearings, we learned that some of the Nation's most gravely ill individuals are under the care of some of the most undertrained medical personnel.

The often brutal sum of this volatile equation demanded first protection for the mentally disabled. Congress attempted to meet that challenge in the months following this committee's work by establishing and funding a nationwide system of advocacy for the institutionalized mentally ill.

At the same time congress is considering a variety of legislation, including my own, to encourage community living arrangements for the mentally disabled. These bills would end the incentive in the Medicaid Program of Federal payments for continued institutionalization and foster the development of comprehensive community-based services, including case management, for the mentally disabled.

As we move on these fronts to protect the mentally ill and to integrate them into the Nation's communities, there remains a crucial, often overlooked item of business. That is the search for medical answers in the field of mental health through research.

In this discipline, there is no mystery so complex, no trauma so devastating, as that of schizophrenia. As the New York Times observed recently after extensive interviews with experts in the field, "its cause is unknown, its progression unpredictable, nor is there any laboratory test capable of providing an undisputed diagnosis."

There is also no certainty of services for those afflicted with mental illness. Because of that, no discussion of funding scientific research into the roots of the disease can take place without a like discussion of services for those who may not be here to reap the benefits of such research. The topics are inseparable.

The promise of research is that we can build upon the clues and the snippets of information to fashion a fabric of stability for the mentally ill, and perhaps even a cure.

Likewise, the search for adequate services has shown that deliberate combinations of nurturing and independence by the health care community can, in fact, result in dramatic change in the lives of mentally ill persons. It is just unfortunate that this is the exception rather than the rule.

The one thing that surely hasn't changed, however, is the toll schizophrenia exacts on the Nation. The Institute of Medicine reports that schizophrenics occupy over one-half of the hospital beds for the mentally ill and retarded in the Nation, and one-fourth of all hospital beds in the United States.

Hollywood's frequent canard about the isolated and violent madman or woman has left a tremendous gulf between truth and the perceptions of the American people on the subject of mental illness, thereby perpetuating the stigma attached to the victims of mental illness and their families.

Fact: Schizophrenia is twice as common as Alzheimer's disease, and 60 times more common than muscular dystrophy. Fact: Some estimates place the annual cost for schizophrenia in America at more than for $40 billion.

Unfortunately, the dry statistics of disease and cost can't convey the full measure of schizophrenia's impact. It is the victims themselves and often their families that bear the greatest burden. It is to them that we turn the committee's attention first this morning.

I would like to say, in introducing the first witness, that this hearing is a direct result of her request to the chairman.

Trish Van Devere Scott asked to see me on the subject. I met several months ago with Trish, who feels very deeply about the subject matter of this hearing, and that it was time that the American people were alerted to the problem at hand.

Her experience in wishing to highlight schizophrenia, I think, proves once again that one person can do something. We have just been through a national election where people had a chance to go ahead and speak about the matters deep in their heart, the matters that were a priority to them.

Very frankly, the Nation failed the test. It failed the test even to take 2 minutes out to go and vote, never mind to get on a train or plane, and come down to Washington, see the chairman, ask for a hearing, have a hearing, and get these facts before the American people, such as is the case with Trish.

I would hope that from this not only do we learn about schizophrenia, but once again the Nation learns the lesson of what it can mean if one or more persons will involve themselves in the problems and the opportunities of this country.

A lot can be done. Those that throw up their hands and walk away get what they deserve. What they deserve, in this case, is a lot of human tragedy that might be averted with a little application of effort and certainly of dollars, also.

Trish, I not only welcome you as a fellow resident of the State of Connecticut and a neighbor, but also I welcome you with great admiration, and I am sure that there are a lot of things that you could be doing, a lot of good times that you could be having, but you are following through on the matter that is dear to your heart.

I have said many times in personal conversations when a loved one dies or when a loved one is in trouble, we all make the statement that if you have your health, you have everything.

We have yet to translate these thousands of personal statements into national policy. This is a translation of a personal belief into what, hopefully, will become national policy.

STATEMENT OF TRISH VAN DEVERE SCOTT, GREENWICH, CT

Ms. Van Devere Scott. Senator Weicker, Mr. Chairman, I thank you very much. I am very grateful to you for having set up this hearing for us.

Senator Weicker. I might add that I am also doubly grateful, because that is the last time, at least for the next 2 years, that anyone is going to address me as Mr. Chairman, and as for the best person to do it, I can't think of a more wonderful person to do it than you. [Laughter.]

Ms. Van Devere Scott. It is indeed an honor.

If they had legs amputated at the knees and they managed to continue their lives in a near normal fashion, we would applaud their courage, admire their commitment, and lend our compassion as well as a helping hand.

The person with schizophrenia, however, can't hold up a CAT scan for the world to see, and thereby, recognize that he, too, is critically disabled, and courageously trying to cope with the worst kind of a curse, a brain gone awry.

The fact that we are here today in Washington, DC, on November 20, 1986, and we don't even know what schizophrenia is, beyond a collection of symptoms that seems to originate in the message control center of the brain, is testimony to historic neglect in this area.

Schizophrenic symptoms are not new to humankind; they are, in fact, ancient. Nor is society's inhumane manner of dealing with the afflicted new. That too is ancient, medieval, Victorian, and present. Shunning, ignoring, and ostracizing is the method. Understanding little, learning less is the credo.

A human being who has lost his or her mind has forfeited his or her life. Whom the gods would destroy, they first make mad. There is a mysterious nightmarish component germane to brain disorder that doth make cowards of us all, striking in our hearts a fear that makes us shrink from facing and confronting what is a confounding sickness.

One almost wishes for an Agatha Christie to step forth and unravel the mystery and present us with the culprit, neatly named. But this is only wishful thinking. The unraveling falls far short of myth and magic and is, instead, research: painstaking, unglamourous research, which costs money.

It requires coordination of efforts and it calls for that crucial kernel of caring needed to engage the elegant engine of commitment.

We are indeed here today asking for an unwaivering committee commitment to solve this cruel mystery of a brain gone awry. And by so doing, I think, we will inevitably solve other problems, disease dilemmas.

Schizophrenia is a curse. It is a key. The major mystery is the brain. We can chemically, mechanically, surgically replace the heart, the kidney, the eyes, other organs, but not the brain.

Once we can reclaim the lost brain, we can reclaim millions of lost souls. That is a challenge of magnitude. It must be designated a prime priority position.

Senator Weicker didn't invite me here today as an expert on schizophrenia. I am not that by any means. But I am a person whose life has been touched and in no small way by the personal tragedy of schizophrenia.

By January 1970, my brother had completed a year of study at Oxford. He had spent the preceding summer using his French, working as a photo-journalist on Le Bien Publique, one of France's oldest newspapers, which also put him very close to his French fiancee, Martine.

In the fall, he entered London's School of Film Technique. I flew to London to spend Christmas holidays with him. While I was there he very modestly showed me his still photo and slide collection. His work was stunning. It was the first time that I really saw my brother as other than my baby brother, and he was a remarkably gifted photographer. I was very pleased and proud.

We put our heads together, and we decided that I would return to London in May, and we would work together on setting up an exhibit of his photos. It was fixed. We parted happily, both of us looking forward enthusiastically to my return in May.

I did return in May. The photographs, the slides, hundreds of them, representing thousands of hours of meticulous work and care, were gone, lost, stolen. His camera equipment gone, his lovely library given away.

On his bar desk lay two lone letters. One from Le Bien Publique offering him his summer job again, and a note from Martine, which was very brief and very sad, his behavior was bizarre so she was leaving.

I looked into his eyes and my brother was absent. The twinkle, the laughter, the droll wit, the ironic nutshell observations, which were his hallmark, they were all gone.

So this time I went to the travel agent to arrange our trip home to find out what the hell was the matter.

We found out, schizophrenia was the matter. Schizophrenia was the diagnosis. Schizophrenia has been our way of life for two decades. That is enough. That is two decades of too much suffering. No one should suffer so much, so innocently.

The talent submerged, the promise broken, the future lost. This is schizophrenia. Waiting for the brain to reconnect.

My brother didn't do this to himself. He didn't drink himself into oblivion. He didn't shoot heroin into his veins. He didn't sniff cocaine. He is as innocent as an elderly person who falls prey to Alzheimer's. He is as innocent as those of any age who fall victim to multiple sclerosis.

Alcoholism, I think, a disease of choice, is embraced and treated in our society. Drug addiction, a habit of choice, has thousands of treatment centers and a Presidential proclamation backed by a multimillion dollar campaign.

I don't begrudge people help, not ever. But I would like to see innocence recognized and rewarded by a rigorous campaign to lift the age old stigma that stifles schizophrenia's innocent victims, by serious and dedicated research and a caring system of services.

There is no choice involved in being schizophrenic. You can't say no to schizophrenia. It isn't a choice. It is thrust upon people at the point of promise. Between ages 18 and 25 is the target for this disease. It steals. It murders, and it leaves desolate recall of what might have been. I think there is nothing more cruel.

One in every 100 Americans will be diagnosed as having schizophrenia, and yet it is spoken of in very hushed terms, if at all. We talk about venereal disease, but we can't stand up and talk about a brain disorder, which might be a virus, an infection of the brain.

The public needs to be educated. They need to know what schizophrenia is and what it is not. It is not a split personality. The message has to get out that there is less violence among most schizophrenics than there is among the general public—not the same—not more—less.

A Government has to help to get that message out. Schizophrenia is a brain disease, we are seeking the cause and cure. It shouldn't necessarily be associated with violence.

If you have a friend or a family member suffering from this, call us, don't keep it a secret. Schizophrenia is not a sin. It is a disease and it can be treated. Please call for a community-based support system near you.

This kind of a message going out on a public service spot makes it something to be dealt with, not feared. A few years ago, most of us probably didn't know Alzheimer's.

What must we do for the afflicted, my brother is one. What he needs is human support, understanding, kindness, in a word, friendship.

I think, perhaps, an approach, and I say these things off the cuff, not really knowing, not being an expert on schizophrenia, but just knowing my brother's needs. If we were to establish almost a Peace Corps of people, intelligent, imaginative, kind people, health professionals, to go out into the community and reach out to those who are crippled by brain disorder, to befriend the friendless. It is far cheaper than recurring hospitalizations.

My brother, by dint of extraordinary concentration, has managed to live independently for years. His three room apartment is immaculately maintained, as is his person, clothes, his car. He gets through his daily chores of shopping, cooking, banking, bill paying, but he hasn't got a friend. And he hasn't got employment. And he doesn't schedule any fun into his day.

He has access to psychiatrists, but, I think, psychiatrists should be encouraged to engage health professionals, who are bright sensitive people.

In my brother's case, someone visiting him a couple times a week, to have a meal, go to see a movie, invite him out, it would be more helpful to him.

Simple things that I can supply when I am there, but I am away a lot. Each time I leave him I know that he is going to be isolated until I get back, but he doesn't have a desire to surrender his autonomy, that he struggles for daily.

Ideally, these health professionals would be available to go with the patient after his first hospitalization, as he tries to resume normal living.

Protected environments are very important to the schizophrenic patient, supportive places, activities, people, sheltered work, educational stimulation, surrogate families, even, with families that are absent. Institutions are inappropriate.

I have spoken with neurologists over the phone, from San Diego to Westchester County. I hear again and again, one phrase, there is a dirth of research on schizophrenia. It has to do with little funding for schizophrenia research. It has to do with many patients being medicated and, thus, not being good for testing.

The communication is so poor from one place to another, perhaps we could establish a national schizophrenia center to coordinate and make available all pertinent research.

A dozen years ago, I worked with Dr. Irving Feller, who established the first burn center in Ann Arbor, MI. He is going to send us guidelines, so that perhaps we could create a few small key schizophrenia treatment centers, specifically to deal with the first time acute episodes, which could be carefully monitored, giving us information we need rather than a haphazard way of local immediate treatment, which loses, or doesn't get the key information in the first place.

Antipsychotic drugs are a treatment, but they are only a stopgap measure on the road to finding the real cause and cure of this most bewildering and perplexing brain gone awry story.

A national schizophrenic center, community support systems, key schizophrenia treatment centers, a health professional peace corps going into the community with the schizophrenic patient, a schizophrenia hotline, crisis assistance, creation and distribution of public awareness materials, there is much that can be done, and much that needs to be done.

All of it requires the investment of money and caring in heavy measure and, I feel, that the reward will be manyfold.

I thank you very much for this opportunity to talk to you on behalf of my brother and myself. Thank you so much.

Senator WEICKER. Trish, thank you very much.

I am going to ask you one question which I intend to pose to every witness before the committee.

Why this difference, both perceptually and as a matter of fact, between mental illness and other diseases? In other words, there seems to be a very clear demarcation line here, that somehow indicates that mental illness isn't a disease, such as heart disease, diabetes, cancer, Alzheimer's.

Why, in our perception, do we set those with mental illness separate and apart, even, if I am not mistaken, in most of the health plans that one can subscribe to, mental illness is either not covered, or covered for some small duration or for some kind of sporadic treatment, but it doesn't fall into the same categories as all the other matters that we refer to as disease.

Why? What do you think causes this?

Ms. VAN DEVERE SCOTT. I guess it is a very old one. Some of it is very recent, what you talked about Hollywood's perception of the mad person. I don't know.

When you were talking, something was going through my mind and it was a picture of just taking someone's head off and separating it from the body. It is as nonsensical as that. It is all one unit, and something that goes awry in one place can easily go awry another place.

Why we have separated the two, I don't know. It is one functioning unit. You can't function without your brain. It is going to control every other organ in your body. To think that it is separate, as an organ, I don't know. If we could do something to change that conception as to why it has come along.

Senator WEICKER. Do you think it might have something to do with the fact that people, even in the year 1986, figure that any mental problem has been created by environment and family, without any sort of a physical cause at all. But rather that it is the fault of family and friends that somebody has a problem over here.

Do you think that might be one of the reasons?

Ms. VAN DEVERE SCOTT. Yes; I think there has been a lot of sociological thought, particularly, and some psychological thought, especially, I suspect in about the last 30 or 40 years, that puts everything in the environment, as opposed to a chemical imbalance.

I think we are leaning toward and learning more that a chemical imbalance, is probably very close to the root of the situation, because some people are in very similar environmental situations, and it doesn't wind up being the same thing.

Senator WEICKER. I have noticed the arrival of my not just esteemed, but very dear colleague, Bill Proxmire, who has served as ranking member during the course of my tenure as chairman.

I don't think either one of us considered each other as ranking or chairman but rather just two people that have the responsibility for their respective parties in providing leadership in the health and science area.

He has been an invaluable member of this committee and I am delighted to have him here.

I believe you have some questions for Trish?

Senator PROXMIRE. Thank you very much, Lowell. I certainly considered you a marvelous chairman. I don't think this subcommittee has had a better chairman ever, although we have had some pretty fine ones over the years.

I think you understand the fine job that Lowell Weicker has done in respect to this subcommittee.

Ms. VAN DEVERE SCOTT. That I do.

Senator PROXMIRE. You pointed out the need for schizophrenia research. This year's committee report contains language urging the development of research programs addressing schizophrenia, and I quote now, "The committee urges the National Institute of Neurological and Communicative Disorders and Stroke [NINCDS] to jointly fund projects with the National Institute of Mental Health [NIMH]."

Now, as I understand it, the thought behind that language was that it makes sense to attack schizophrenia as we have Alzheimer's disease and Huntington's disease, and not simply as a behavioral problem. Does that make sense to you?

Ms. VAN DEVERE SCOTT. Yes; brain research. It could even widen my concept of a national schizophrenia center to a brain research center, and have all things in there that had to do with the brain.

Senator PROXMIRE. The story of your experience with your brother was very, very moving. Did that experience give you a feeling that this was something that had a physical cause, not an environmental cause or some external element that affected it?

Ms. VAN DEVERE SCOTT. No; I always wish, especially when I mentioned the schizophrenia treatment center, that very, very minute patient profiles on the patients, and the patient could be monitored, and some of their background and history, mental, physical, medical could be taken very carefully. So those kinds of profiles could be compared.

But I will have to say in my brother's case, and it is why I chose 1970, because he had been functioning very well, and it wasn't something that suddenly happened to him as a series of traumas or calamities.

He had not been suffering and functioning poorly prior to that. He had been doing very well, traveling, studying, working, involved socially with people.

In 6 months it was like that. I can't see that that would necessarily come about in a normal course of things without a trauma, which did not happen.

Senator PROXMIRE. Thank you very much.

Thank you, Mr. Chairman.

Senator WEICKER. Thank you.

Another question, which I pose to you, and will pose to all the other witnesses, is that I wonder whether or not we, in Government, haven't unintentionally created this separation of mental illness from the rest of disease, by having a National Institute of Mental Health, separate from the National Institutes of Health [NIH], where the various diseases come under that umbrella. So, even, in governmental structure we have two different approaches here.

Ms. VAN DEVERE SCOTT. Yes; that could very well be. Thinking of it in a schism, perhaps, creates it. It is dealt with as something foreign, as opposed to looking at it in a totality, when the entire human system is a totality.

Senator WEICKER. How is your brother functioning now? Is he under active treatment with drugs, or whatever treatment is available?

I wish you would explain that to us what is available to a schizophrenic, since you have a brother who is one. What is available that gets him through the days?

Ms. VAN DEVERE SCOTT. He has access to psychiatrists, and quite frankly, the 50-minute hour doesn't serve him very well, not at all.

Someone with much more contact with him would serve better, even if he were to see someone in their office three, four, five times a week.

I think, in the treatment, in the care, what is very missing is the transitional steps and the continuity of support and the transitional lengths. Somebody can go and be hospitalized, be medicated, at a time of an acute episode, and then they are thrown back out without followup, without transitional support.

I think, this is the main thing that is needed, here, is somebody that takes care of it from the beginning, and is closely monitored and kept in a rehabilitation and recovery, and resuming normal living situations, very supportive and very tuned in.

PREPARED STATEMENT

Senator WEICKER. Thank you for your testimony. Your statement in its entirety will be included in the record. Mainly, I thank you for bringing this whole thing together here. I think before the day is over it will be a very important educational experience for the U.S. Senate.

Ms. VAN DEVERE SCOTT. I thank you for the opportunity, Senator.

[The statement follows:]

STATEMENT OF TRISH VAN DEVERE SCOTT

If they had legs amputated at the knees and they managed to continue their lives in a near normal fashion - we would applaud their courage, admire their commitment, and lend our compassion as well as a helping hand.

The person with Schizophrenia, however, cannot hold up a CAT Scan for the world to see - and thereby recognize that he too is critically disabled - and courageously trying to copy with the worst kind of a curse - A Brain Gone Awry!

The fact that we are here today in Washington, D.C. on November 20, 1986 and we don't even know what Schizophrenia is - beyond a collection of symptoms that seems to originate in the message control center of the brain - is testimony enough to the shameful and historic neglect in this area.

Schizophrenic symptoms are not new to humandkind - they are in fact - ancient. Nor is society's inhumane manner of dealing with the afflicted new - that too is Ancient, Medieval, Victorian, and Present ... shunning, ignoring, ostracizing is the method ... understanding little, learning less is the credo ... with no real commitment to finding the cause, the cure - and alleviating the cost of human agony, misery and torture. A human being who has lost his or her mind has forfeited his or her life. Whom the gods would destroy they first make mad. There is a mysterious nightmarish component germane to brain disorder that doth make cowards of us all - striking in our hearts a fear that makes us shrink from facing and confronting a Confounding Sickness.

One almost wishes for a P.D. James or an Agatha Christie to step forth and unravel the mystery and present us with the evil culprit neatly named and tagged! But this is only wishful thinking. The unraveling falls far short of myth and magic - and is instead - research - painstaking and unglamorous. And research costs money, and it requires coordination of efforts, and calls for that crucial kernal of caring needed to engage the elegant engine of commitment.

And we are indeed here today to crusade for an unwavering commitment to solve this cruel mystery of A Brain Gone Awry - and by so doing - we will inevitably let flow a rich sea of knowledge - which will undoubtedly - in its wake - provide the solution to myriad disease dilemmas. Schizophrenia is the curse/Schizophrenia is the key. The major mystery is the Brain. We can mechanically/surgically replace the heart, kidney, eyes, other organs ... but the brain ... When once we can reclaim the lost brain - we can reclaim millions upon millions of lost souls. That is a challenge of magnitude. It must be designated a prime priority position.

Senator Weicker did not invite me here today as an expert on Schizophrenia - I am not that - not by any means. But I am a person whose life has been touched and in no small way moulded by the personal tragedy of Schizophrenia.

This story is not easy to tell.

1970. By January of 1970 my brother had completed a year of study at Oxford. He had spent the preceeding summer using his fluent French by working as a Photo-Journalist on "Le Bien Publique" - one of France's oldest newspapers - in Dijon - which also put him close to his very charming French fiancee, Martine. In the Fall he entered London School of Film Technique. I flew to London to spend Christmas Holidays with him. When he picked me up at Heathrow he warned me: "Watch out for the traffic, Trish!" Well, I did watch out for the traffic - but the wrong way, and I was hit by a car on Christmas Eve. He rushed me to the hospital. I emerged with a cane, grateful for my life, but badly bruised. So he thought it a good idea to get me out of his cold London flat - and arranged a trip to take me to Morocco for a week where I could mend more comfortably and he could take photographs. Upon our return to London I studied his still photo and slide collection. His work was stunning in its depth, technique, subject and structure. This was the first time that I really saw him as other than my baby brother! He was a remarkably gifted photographer! I was very pleased and proud. We put our heads together and decided that I would return to London in May - right after I finished shooting a film I was scheduled to do that Spring. We would work together on setting up a modest exhibit of his photo work. It was fixed. Both of us looking forward to my return in May with great enthusiasm.

I did return in May. The photographs, the slides - hundreds and hundreds of them - representing thousands of hours of meticulous work and care - were gone ... lost or stolen. His camera equipment - gone. His lovely Library given away. On his bar desk lay two lone letters. One from Le Bien Publique offering him his summer job again - if he wished it - and a note from Martine - sad and brief - his behavior was bizarre so she was leaving. I looked into his eyes - and my brother was absent. The twinkle, the laughter, the droll wit and the ironic nutshell observations which were his hallmark ... all gone. So this time it was I who went to the travel agent to arrange our trip ... our trip home - to find out what the hell was the matter. We found out. Schizophrenia was the matter. Schizophrenia was the diagnosis. Schizophrenia has been our way of life for nearly two decades. THAT IS ENOUGH. That is two decades of too much suffering. No One should suffer so much - so innocently.

The talent submerged, the promise broken, the future lost, the life taken. This is Schizophrenia. Aimless, hopeless, wandering, waiting ... waiting for the Brain to re-connect.

My brother did not do this to himself. He did not drink himself into oblivion. He did not shoot heroine into his veins. He did not sniff cocaine. He is as innocent as an elderly person who falls prey to Alzheimer. He is as innocent as a person of any age who falls victim to multiple sclerosis. Alcoholism - a disease of choice - is embraced and treated in our society. Drug addiction - a habit of choice - has thousands of treatment centers ... and a Presidential Proclamation backed by a multi-million dollar campaign. I don't begrudge people help - not ever. But I would like to see innocence recognized and rewarded by serious and dedicated Research, and a caring system of services, and a rigorous campaign to lift the age-old stigma that stifles Schizophrenia's innocent victims. There is no choice involved in being Schizophrenic. You can't "Say No" to Schizophrenia. It is not a choice. It is thrust upon the innocent at the point of promise ... as they turn into adults. The target age for this disease is 18 to 25. It steals. It murders. It leaves bereft. It takes away hope, promise, and joy. It leaves despair, emptiness ... and desolate recall of what might have been. There is nothing more cruel.

I would like to see compassion extended. I would like to see ignorance replaced by a commitment to find out - what is this thing called Schizophrenia that squanders lives so recklessly and runs rampant among us. One in every hundred

Americans will be diagnosed as having Schizophrenia ... and yet it is spoken in hushed tones - if at all! We can talk about venereal disease - but we cannot stand up and talk about a Brain Disorder - which might be a virus - an infection of the brain!

I would like to see the closing years of the twentieth century as the time when "the clarion call" went out to solve the mystery of the brain - and that call was answered - and the culprit cut down - and those so mercilessly bound - were set free. We cannot consider ourselves a Society of Conscience if we allow Schizophrenia and the Stigma of Schizophrenia to reign unchecked.

The public needs to be educated. They need to know what Schizophrenia is and what it is not. It is not a split personality. It is not Dr. Jekyl and Mr. Hyde. That is a very rare form of hysteria. And most importantly they need to know that the incidence of violence among Schizophrenics is LESS than that among the 'normal' population. Less - not more. Not the Same. Less violence. Our government must help to get the message out to the people. Schizophrenia is a brain disease, we are seeking the cause and cure. It is not a split personality. It should not be associated with violence. If you have a friend or family member suffering from this - call us - don't keep it a secret. Schizophrenia isn't a sin. It is a disease and it can be treated. Please call for a community based support system near you. This kind of message going out on public service spots makes it something to be dealt with - not feared. A few years ago most of us did not know about and could barely pronounce Alzheimer.

Once better informed people will be more receptive to having half-way houses on their block.

What must we do for those afflicted - who walk among us - muted - gray - almost invisible - my brother is one. What he needs is some human support, understanding, kindness - in a word - Friendship.

I think we need to take a fresh approach ... perhaps establish and maintain a Peace Corps - if you will - comprised of intelligent, imaginative, kind people armed with common sense and some intensive training who will go into the community and reach out to those who are crippled by brain disorder. To befriend the friendless.

In the long run it would be far cheaper than the cost of frequent recurring hospitalizations. And certainly kinder in every way for the afflicted.

My brother - by dint of extraordinary concentration that is in itself exhausting - has managed to live independently for years. His three room apartment is immaculately maintained - as is his person, his clothes and his car. He gets through his daily chores of shopping, cooking, banking, bill-paying. But he hasn't got a friend. And he hasn't got employment. And he doesn't schedule any fun into his day. He has access to psychiatrists. But the fifty-minute-hour serves him poorly. In fact psychiatrists - who do not have close associations with community supported systems should be discouraged from seeing Schizophrenic patients on a regular basis. It wastes the tax-payer's money [the private family's money] and most importantly it seldom helps the patient - in and of itself. Psychiatrists should be encouraged to engage para-professionals - bright, sensitive, health professionals. In my brother's case - someone visiting him a couple times a week - to have a meal - see a movie - invite him to a dinner - plan an activity would be much more helpful to him.

Just simple things that I can supply when I'm there. But I am away a lot. Each time I leave I know that he will be isolated until I return. Yet he has no desire to surrender the autonomy that he has and struggles for daily.

Training a corps of para-professionals or health professionals to go out into the community and deal on a daily basis with Schizophrenics - might at first sound expensive - but the alternative is much costlier - and the third alternative is simply immoral.

Ideally these health professionals would be available to go with the patient after his first hospitalization as he tries to resume normal living - this is wise protection against another acute episode and another hospitalization.

Protected environments for the Schizophrenic is so important. There are some - but far too few. Supportive places, activities, people, sheltered work, educational stimulation. Surrogate families and homes where the family is absent and institutions are inappropriate.

I have spoken over the phone with Neurologists, Neuro-psychiatrists, from San Diego to Westchester County. I hear again and again one phrase: There is a Dirth of Research on Schizophrenia. Partly because there is so little funding for Schizophrenic research - another difficulty being that so many of them are medicated thus interfering with testing. And the communication from one place to another is so poor. This gave rise to several thoughts - in research, service, and public awareness.

We could certainly establish a National Schizophrenic Center to coordinate and make available all pertinent research. I have talked to doctors who study sleep disorders as well as Schizophrenia about the possibility of the Schizophrenic being awake and asleep at the same time - that a chemical message is blocked - and the sleep state does not recede when the person wakens - and he is therefore confronted with both states simultaneously. No foreground; background - just two foregrounds. Half a dozen doctors said they had heard of that theory "awhile back" but that it had not been pursued - or it had not gone anywhere - or it needed more looking at - but any person with Schizophrenia who was on medication was not a candidate for research - either for sleep disorder or for comparisons. A National Schizophrenic Center could indeed coordinate research projects.

A dozen years ago I was on the board of one of the first Burn Centers in Ann Arbor, Michigan. The need for highly specialized treatment for such cases had clearly been established. People were dying needlessly all around the country because the average hospital situation hadn't the skill to deal with such an emergency. As new Burn Centers came into existence they all hooked up to one computer so a patient could be monitored by all the specialists be they in Texas or Michigan.

Perhaps in addition to a Nationally Headquartered overview center, we could create a few small Key Schizophrenic Treatment Centers specifically to deal with first time acute episodes - which could be carefully monitored - giving us information that we need - rather than this haphazard way of local immediate treatment - which loses - or doesn't get key information in the first place.

Anti-psychotic drugs are a treatment - but they are only a stop-gap measure on the road to finding the real cause and cure of this most bewildering and perplexing Brain Gone Awry story.

A National Schizophrenic Center could encourage guidelines for community support systems ... encouraging funding for, expansion of, and imitations of the good ones that already exist.

Also - it could help shape selection of and training for a health professional "peace corps"; "task force" to go out into the community with the Schizophrenic patient as they return to normal life.

The establishment of a Schizophrenia Hotline/crisis assistance.

And the creation of and distribution of public awareness materials and information.

There is much that can be done. Much that needs to be done. All of it requires an investment - of money and caring in heavy measure ... but I do feel - even predict that the reward will be manifold.

And surely, we must not - forget, neglect, ignore any longer - that is too merciless an alternative to even consider or contemplate.

STATEMENT OF E. FULLER TORREY, M.D., BETHESDA, MD

Senator WEICKER. The next witness is Dr. E. Fuller Torrey, a clinical and research psychiatrist in Bethesda, MD.

Dr. Torrey, it is very nice to see you.

Dr. TORREY. Thank you very much, Senator Weicker, Senator Proxmire. I am most grateful for the opportunity to be here this morning.

This is a very important disease and a very neglected disease. The best figures we have estimate that about 1.6 million Americans are affected with this disease this morning. This is the same number of people who live in the State of Nebraska, or the State of Utah, or the States of Vermont and New Hampshire combined.

As you pointed out it is twice as common as Alzheimer's disease. It is five times as common as multiple sclerosis, six times more common than insulin-dependent diabetes, 60 times as common as muscular dystrophy. It is a very common disease that affects members of the families of this subcommittee and many other families in Congress. It also affects my family.

My sister, who was normal until she was 18, was affected with schizophrenia. She has been hospitalized almost continuously for 25 years with a more severe form of the disease.

Today I want to testify not only for myself, as a clinical and research psychiatrist who has specialized in schizophrenia, but I am testifying for my sister and, hopefully, will make some of the points that she would make if I had been the one who had been sick with this disease.

I want to talk about research and if we have time, briefly about services and stigma.

I think research is the primary issue, because that is indeed a Federal prerogative. The Federal Government doesn't do very many things very well, but it does well in research on major diseases.

In 1946, the Federal Government set up the National Institutes of Mental Health. The purpose of it was to be a research institute on major mental diseases, primarily schizophrenia. Schizophrenia research was to be the cornerstone of NIMH when it was set up.

Over the years NIMH went off in all directions. It pursued poverty discrimination, urban housing, and every other social and economic problem known to man. As it went on, it left the National Institutes of Health in 1968, and schizophrenia became less and less important, so that rather than being the cornerstone of the Institute, schizophrenia instead became a pebble lying beside the path toward a social brave new world.

Over the last many years, less than 10 percent of the research budget of the National Institute of Mental Health has gone to schizophrenia research. Where has the other 90 percent gone?

It has gone to a variety of projects, some of which I list and I won't go over, training student leaders for changes on campus, the impact of religious belief on voting behavior, factors in the marriages of older couples, effects of automation on the lives of longshoremen.

Many of these are very worthy projects. Many other unfortunately are good candidates for Senator Proxmire's golden fleece award. The point is that they were done in place of doing more research on schizophrenia.

Schizophrenia has, for research funds, in the United States today, $17 for every person affected with this disease, multiple sclerosis has $161, cancer has $300, and muscular dystrophy has $1,000.

This is the most neglected research disease in the United States. It is also one of the most expensive. The cost of schizophrenia has been estimated at at least $40 billion in the United States. I think, to give a couple of case examples is a way to understand how expensive this is.

My sister, for example, in the New York State hospital system has been there 25 years. The cost of her hospitalization alone is just under $1.5 million today, that doesn't include lost wages, doesn't include expenses to my family, et cetera.

On the ward that she is on in the hospital, there are 22 other patients. In the hospital she is in, there are 53 other wards. In the United States, there are 263 other State hospitals like this State hospital.

To give you another example, in 1980–81, I was in charge of one of the divisions of St. Elizabeths' Hospital. We had a long-stay ward with 24 patients with schizophrenia. Their combined total time in the hospital was over 1,000 years, added together.

The cost of their hospitalization, in today's dollars, is $82 million. That means that the patients on that one ward have cost in State, and in this case, Federal funds, four times what we have spent on schizophrenia research last year, which was $21 million.

Economically we have been very foolish in spending so little on research on this disease, for even small advances would literally save billions of dollars.

Two points: Don't let anybody tell you that we don't know what to do with schizophrenia research. There are a lot of good ideas, we simply haven't pursued them. For example, with other diseases, we pursue research on identical twins to try and separate the genetic from the nongenetic aspects of the disease. Over the 40 years of NIMH's existence, they have funded one twin research, studying 17 twin pairs.

Another factor is to look at families where two or more members are affected. At no time during the 40 years has NIMH ever set up a research unit to study families in which two or more members are affected.

People falling ill for the first time, every other disease we set up research units to get them on the ward, draw blood before you give medication, these kinds of things, but we have never set up a research unit to do this for schizophrenia.

The medications we have available, we have now about eight different medications available. We have yet to do basic research to find out which medications should be tried first in which patient.

Also, let nobody tell you that NIMH doesn't have the latitude to do research on this if it so chooses. The Federal Government has stimulated research on alcoholism, Alzheimer's disease, acquired immune deficiency syndrome [AIDS], most recently, cancer, we have all the latitude we want, if we want to carry it out.

For example, in 1980, both schizophrenia and Alzheimer's disease were receiving about $13 million in Federal research funds. In 1986, schizophrenia has risen to $21 million but Alzheimer's disease has risen to $54 million. That is a disease we became interested in. We could become interested in schizophrenia if we so chose.

Let me just say, as an aside on the current direction of NIMH, I have a great deal of personal and professional respect for Dr. Frazier, who will testify later. He has started things in the right direction, however, the inertia in the Institute is absolutely overwhelming, since they have neglected the disease for so long.

He has increased the number of people who develop research grants, and he has increased the total funding. He is the first Institute director in 40 years to do anything with this disease. His predecessors, including Dr. Pardes, who will also testify, did nothing to increase schizophrenia research funds by a percentage of the total research funds for NIMH.

We shouldn't have to wait 40 years for a director to come along who is interested in this disease. It should be built into the Institute. It should be part of their job.

What can the Federal Government and your committee do about this? Three things in terms of the research. First, we have got to increase the funds for schizophrenia, $20 million for a disease that is costing a minimum of $40 billion a year is a very silly expenditure.

I am proposing a triple double for those who follow the National Basketball Association, this isn't points-assisted rebounds, this is doubling the schizophrenia research, each, for the next 3 years, from $20 to $40, $40 to $80, $80 to $160 million. Then we would be probably about the level where we could start to make some inroads and ultimately decrease cost on it.

Second, NIMH should be returned to the National Institutes of Health. There is no rational reason why it was moved out in 1968, except territoriality, and there is absolutely no reason why it shouldn't be moved back today.

Third, I would suggest consideration be given to not only moving NIMH back into the National Institutes of Health, but in amalgamating it with the Neurological Institute, the NINCDS, where other brain research is going on. At one time, 1951 to 1960, in fact, they had joint research programs. Research on brain disease, such as schizophrenia and manic depressive psychosis, would then be under the same administrative roof as research on brain diseases such as multiple sclerosis, Alzheimer's disease, stroke, and Parkinson's disease.

Let me just say two words on services and stigma before I close. Services, the Federal Government became involved in after the war and, in fact, in 1961, when my sister entered the hospital, was just the time when we were kicking off the Community Mental Health Center Program.

Over that time we have spent some $3 billion on 800 community mental health centers. We have also funded the training of mental health professionals up to, in the early 1970's, $110 million a year. What has that gotten us? That has gotten us almost nothing for schizophrenia.

It has gotten us community mental health centers which specialize in marital coupling——[Laughter.]

Dr. TORREY. I hope they don't do that—in marital counselling of couples. It has gotten us a large group of mental health professionals who are in private practice seeing problems of living people who have interpersonal problems, but not people who have schizophrenia.

If you want to know how bad services are for schizophrenia, I suggest that you simply look at the last page of the testimony that Dr. Frazier is going to offer. He has a chart on the distribution of adult schizophrenics in the United States today.

On that chart 58 percent are listed as care unknown. I think that that tells you a great deal about what is going on. If you want to know where this 58 percent are, I suggest you go about six blocks to the west, to the Second and D shelter, where last night 800 individuals stayed, of those 800 men approximately 200 have schizophrenia and are untreated.

Or you can go about 10 blocks north to the Emery School, where last night 120 women stayed, of those, approximately 60 have untreated schizophrenia. There are an additional about 15 shelters in this city with the same percentages of schizophrenics in them.

Finally, on stigma, again, I think all of you know this is a terribly stigmatized disease. I would only ask you how you would feel if you had a disease, yourself, that was portrayed on television as always violent and aggressive?

In the most recent survey that we have, 73 percent of television characters labeled as mentally ill were portrayed as violent, and 23 percent were portrayed as killers.

If you had diabetes, and you had 73 percent of your diabetics on television portrayed as violent, and 23 percent as killers, I think, you, yourself, can figure out how you would feel about having this disease.

I think the Federal Government has relatively little to do with services, except for programs, relatively small like the community support program. I think they can do relatively little on stigma, except doing an educational campaign through NIMH, but you can do a great deal on research.

In summary, schizophrenia is a brain disease whose causes can be found. It is true that we haven't found them. It is also true that we haven't looked very hard.

My sister wants to know why she has had to stay in the hospital for 25 years, without any research going on, I would like to know, I think all the families that are affected with this disease would like to know, and I thank you for the opportunity to testify.

PREPARED STATEMENT

Senator WEICKER. I thank you very much Dr. Torrey. We will insert your statement in its entirety in the record at this point.

[The statement follows:]

STATEMENT OF E. FULLER TORREY

I am grateful for the opportunity to appear before you this morning to discuss schizophrenia. Although seldom talked about in public forums such as these Hearings, schizophrenia is in fact the most neglected disease in the United States. A minimum of 1.2 million individuals in this country have signs and symptoms of schizophrenia today. (1.2 million is a minimum number; the National Institute of Mental Health (NIMH) has estimated the number affected to be 1.5 million and others have estimated up to 2 million). It is twice as common as Alzheimer's disease, five times more common than multiple sclerosis, six times more common than insulin-dependent diabetes, sixty times more common than muscular dystrophy. It affects the families of members of this Subcommittee and other members of Congress.

Schizophrenia also affects my family. My younger sister, Rhoda, became sick with this disease in 1957 when she was 18 years old. She was hospitalized at university medical centers in New York and Boston with little improvement and since 1965 has been hospitalized almost continuously in state hospitals in New York State. Today I am testifying not only as a clinical and research psychiatrist whose speciality is schizophrenia; I am also testifying for my sister, and I want to convey to you her concerns as I would want her to have conveyed my concerns if I had had the misfortune to have been afflicted. Our concerns are three: services, research, and stigma.

Services for Schizophrenia

Regarding services, when Rhoda was first afflicted with schizophrenia in 1957 it was at the same time as meetings of the Joint Commission on Mental Illness and Health were taking place in Washington. Established by Congress, the purpose of the Joint Commission was to investigate the deplorable services available for persons with serious mental illnesses and to make recommendations for improvement. In 1961 the Joint Commission issued its report (Action for Mental Health) and proposed a series of mental health centers in the community to treat the seriously mentally ill closer to home. The idea was adopted by President John Kennedy as "a bold new approach" and legislation eventually was passed in 1963 to fund an initial 400 Community Mental Health Centers with federal funds. For Rhoda, entering the state hospital at the same time as the Joint Commission was issuing its report, there was the promise of better services in the future for people like herself.

What has happened during the 25 years Rhoda has been in the hospital? Congress allocated funds for the establishment of over 800 Community Mental Health Centers (CMHC's), allocations totaling over 3 billion dollars. And to insure that there would be enough psychiatrists and other mental health professionals to staff the Centers, Congress for many years also gave the National Institute of Mental Health up to 110 million dollars a year for training of psychiatrists, psychologists, psychiatric social workers and nurses. But as far as Rhoda and other persons with schizophrenia are concerned it was simply a waste of money. Neither the Community Mental Health Centers nor the newly trained professionals took much interest in patients with serious mental illness like schizophrenia, but chose instead to do psychotherapy on persons with life crises of various kinds. Federal programs originally set up for the seriously sick became coopted instead for the worried well.

Some persons today even deny that the Community Mental Health Center program was set up to provide services for the seriously mentally ill. Anyone who doubts, however, need only look at the Congressional hearings at which it was clearly stated, over and over, that the purpose of the proposed CMHC's was to "move the care of the mentally ill into the community and out of these large mental institutions."(1) Each year officials

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(1) Hearings on "A Bill to Provide for Assistance in the Construction and Initial Operation of Community Mental Health Centers," Subcommittee on Public Health and Welfare, Committee on Interstate and Foreign Commerce, March 26-28, 1963.

of the National Institute of Mental Health returned to Congress to ask for more funds for the CMHC's and more funds for training mental health professionals. Each year thousands more seriously mentally ill persons were deinstitutionalized from state hospitals -
358,000 between 1965 and 1980. And yet from the early 1970's onward the evidence was clear - to NIMH and to anybody who wished to look - that the Community Mental Health Centers were not serving the seriously mentally ill and the newly trained professionals had gone off to the private practice of psychotherapy.(2) The consequences? Today you have literally hundreds of thousands of persons with schiozphrenia deinstitutionalized from state hospitals yet receiving psychiatric services which vary from grossly inadequate to nonexistent.

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(2) "The only people [in CMHC's] with improved lives appear to be the professionals who run the program." E. F. Torrey and R. L. Taylor, "A Minuet of Mutual Deception: NIMH and the Community Mental Health Centers." NIMH internal memo, May 8, 1972.

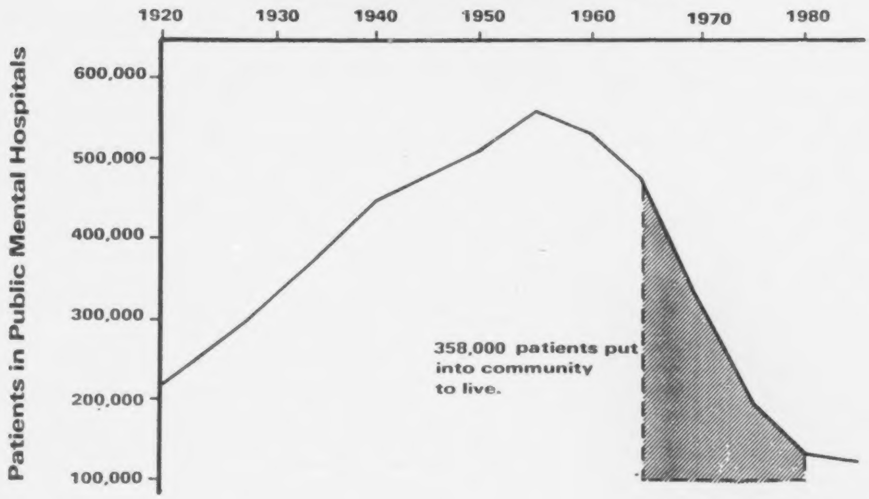
"In ranking of 10 service process goals by 175 centers [CMHC's], the goal of decreasing state hospital utilization was ranked next to last." F. Baker et al. "Study of the Relationship Between CMHC's and State Mental Hospitals." NIMH contract report, August 1972.

"The deficiencies of the [CMHC] program are now too glaring to be brushed aside." F. D. Chu and S. Trotter, The Madness Establishment (New York: Grossman, 1974).

"Some centers consciously discriminated against poor and chronically ill patients who came to them for help." Report of American Psychiatric Association, quoted in Chu and Trotter.

"There was no consistent relationship between the opening of centers [CMHC's] and changes in state hospital resident rates." C. Windle and D. Scully, "CMHC's and the Decreasing Use of State Mental Hospitals," Community Mental Health Journal 12:239, 1976.

THE DEINSTITUTIONALIZATION OF AMERICA'S SERIOUSLY MENTALLY ILL



358,000 patients put into community to live.

Research on Schizophrenia

Regarding research on schizophrenia, the National Institute of Mental Health was established by Congress in 1946 as a research institute, part of the National Institutes of Health. President Truman and leaders in Congress were deeply concerned by the number of America's young men who had been rejected or discharged from military service because of serious mental illnesses during World War II, and NIMH was created in order to promote research on the causes of these illnesses. Research on schizophrenia and other serious mental illnesses was to be the cornerstone of NIMH.

It was suspected in 1946, and has become abundantly clear since, that schizophrenia is a brain disease. It is in exactly the same category as multiple sclerosis, Alzheimer's disease and Parkinson's disease; like these other brain diseases, schizophrenia requires research to elucidate its precise causes and to develop improved treatments. NIMH, however, had other things in mind and rode off madly in all directions in pursuit of poverty, discrimination, urban housing, and every other social and economic problem known to man. Research on schizophrenia receded ever farther into the distance with each passing year, and by the time NIMH left the National Institutes of Health in 1968 to become autonomous, schizophrenia research had become almost invisible in NIMH's priorities. What originally had been the cornerstone had become instead a pebble lying beside the path toward a social brave new world.

Since 1980 NIMH has spent less than 10 percent of its research funds on schizophrenia-related research; this was $21.1 million dollars in FY 1986. What has it spent the rest of its money on? A perusal of grants funded since 1970 turns up the following as examples of where the money has gone:

1971	Training Student Leaders for Changes on Campus	$ 65,000
	Pupil Growth In and Out of School	33,000
1972	Methods to Promote Growth in Marital Relationships	126,000
	An Empirical Base for Planning Community Changes	162,000
1973	Problem-Solving Behavior of Family Groups	194,000
	Human Territoriality in Home and Neighborhood	21,000
1974	Study of Process of Adjustment of Families of Prisoners	$169,000
	Earned Family Incomes and the Urban Crisis	210,000
1975	The Impact of Religious Belief on Voting Behavior	14,000
	Tenant Organization: Mobilization and Consequences	82,000
1976	Effect of Metropolitan Open Space on Community Life	72,000
	Factors in the Marriages of Older Couples	15,000
1977	Culture and Cooperation	53,000
	Oral History and World View	33,000
1978	Managing Grievance in the Urban Workplace	77,000
	Effects of Automation on the Lives of Longshoremen	34,000
1979	Pair-Bonding, Parental Care and Reproduction	44,000
	Self-Regulation in Altruism	39,000
1980	Sex and Sexual Violence in Fiction	49,000
	Police Discretion in Relationship to Emergency Apprehension	75,000

How has this been allowed to happen? Why has schizophrenia, occupying half of the psychiatric hospital beds in the United States, been given such a small portion of NIMH research funds? For every patient with schizophrenia only $17 is spent on research. Compared to other diseases, for every patient with multiple sclerosis $161 is spend for research; for every patient with cancer, $300; for every patient with muscular dystrophy, over $1,000. Why is schizophrenia the most neglected disease research-wise in the United States?

Research funds for schizophrenia should be justified on humanitarian grounds alone. They can also be justified on economic grounds, for schizophrenia is a very expensive disease. Estimates by federal officials of its cost in the United States range between $18 and $48 billion per year. My sister, for example, has now been hospitalized in state hospitals for 25 years. The current patient cost per day in New York State mental hospitals is $161.57. In today's dollars that means that Rhoda's hospitalization has cost New York State $1.47 million over the 25 years. The wards in her hospital average 22 patients; if the other patients on her ward are like Rhoda the total hospitalization cost to date for that single ward would be $32.3 million for the 25 years. There are 53 other wards in Rhoda's hospital. There are 263 other state hospitals in the United States like Rhoda's hospital. Yet we spent only $21.1 million on schizophrenia research last year.

Let me give you another example. In 1980-81 I was the director of one of the divisions of St. Elizabeths Hospital here in Washington. We set up a ward for long-stay patients with schizophrenia. There were 24 men on the ward and their combined time in the hospital totaled over one thousand years. The cost per patient per day at St. Elizabeths is now $224.47. In today's dollars those 24 men alone have cost over $82 million in hospitalization costs, almost four times what we spent for research on this disease last year. Economically we have been very foolish in spending so little on research on this disease, for even small advances in treatment would result in savings of literally billions of dollars.

Let nobody tell you that we are not spending money on schizophrenia research because we do not know what to do. We have many good leads which we simply have not pursued. For example research on twins with schizophrenia is an excellent way of sorting out genetic factors from non-genetic factors causing this disease. Yet in the 40 years NIMH has had responsibility for schizophrenia research, until the present they have funded only one twin study consisting of 17 pairs of twins. Studies of families with two or more members with schizophrenia is another excellent approach, yet NIMH has never set up a research ward to study such patients nor funded this research elsewhere. NIMH has not even set up a research unit to study patients falling ill for the first time so that basic measurements (e.g. blood studies) can be made before medications, which confuse many measurements, have been given. Nor has NIMH funded basic studies of which of the several medications available should be tried on which patient first. These are basic research approaches which have been used fruitfully for other major diseases but not for schizophrenia.

Some people may tell you that NIMH has no latitude in determining what research is funded, and can only respond to grants submitted by researchers. Anyone in the research establishment can tell you that this is nonsense. Federal research programs initiate research ideas all the time through grants and contracts; it was done to increase research on cancer, alcoholism, Alzheimer's disease, and is now being done for AIDS. It could certainly be done for schizophrenia if NIMH wanted to do so. The current NIMH Director, Dr. Shervert Frazier, has shown more interest in schizophrenia than his predecessors but to date no major shift of research funds to this disease has occurred. In research terms we should be talking of a Manhattan Project when in fact we are quibbling over small segments of the Lincoln Tunnel.

Stigma on Schizophrenia

Regarding stigma, there is no chronic disease in the United States with more social stigma attached than schizophrenia. It is the leprosy of the twentieth century. Families try and hide it and use euphemisms such as "nervous condition" or "nervous breakdown." Individuals with schizophrenia are discriminated against in housing, education, vocational rehabilitation and jobs. Most people do not even know what schizophrenia is, often mistaking it for the very rare condition (dissociative disorder) involving multiple personalities. One recent poll found that 55 percent of the public does not believe that mental illness exists, and only 1 percent believe that mental illnesses are a major health problem.(3) On television persons with schizophrenia are portrayed as usually violent and assaultive when just the opposite is in fact the rule; one study reported that 73 percent of television characters labeled as mentally ill were portrayed as violent and 23 percent of them as killers.(4) Newspapers and magazines headline the occasional person with schizophrenia who does become violent, but rarely mention the other 50 or 100 persons with this disease who are the victims of violence because they are unable to adequately defend themselves.

On a personal note I have experienced the stigma of schizophrenia in my family as have all families with this disease. If my mother were still alive I could not have testified today because she would be afraid that others would find out that my sister has this disease. Personally I am proud of my sister - proud that she has continued to fight to lead a normal life despite years of hospitalization, proud that she has retained her sense of humor, proud that she is determined to live in the community. Since we now know that schizophrenia is a brain disease in exactly the same sense as multiple sclerosis, Alzheimer's disease and Parkinson's disease, there should be no more stigma attached to it than there is to these other brain diseases, or kidney diseases or diabetes. Having schizophrenia is enough of a burden and tragedy; by stigmatizing those who have it we have needlessly made it into a living hell both for patients and their families.

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(3) C. Holden, Science 232: 1084, 1986.
(4) G. Gerbner *et al.*, *New England Journal of Medicine* 305: 901, 1981.

What Should Be Done?

What does all this have to do with your Subcommittee? As the body providing official oversight of the NIMH budget I believe it has much to do with you. Recommendations for possible actions are in three areas:

Services: Services for the seriously mentally ill have been the responsibility of individual states since the founding of the United States and should remain that way. The ineffectual foray of the federal government into mental health services via CMHC's does not make one sanguine about recommending further federal efforts on services for the seriously mentally ill. Probably the most sensible service activities for NIMH are:

A. Continuation of the successful Community Support Program (CSP) providing funds for demonstration projects.

B. Information exchange and publicizing those programs for the seriously mentally ill which appear to be working.

C. Research on mental health services for the seriously mentally ill, e.g. determine what works, which service alternative is more cost-effective, etc. This research area is virtually virgin ground.

Research: Research on all major diseases is a federal responsibility.

A. Research funds for schizophrenia should be increased dramatically. Perhaps the best way to do this, to borrow a term from professional basketball, is a "triple double." In this context a triple double has nothing to do with points, assists, and rebounds but rather suggests that NIMH's research budget for schizophrenia should be doubled three years in a row - to $40 million in FY 1987, $80 million in FY 1988, and $160 million in FY 1989. Then we would be at about the level we should be at. Much of the initial year's increase would not necessarily have to be new money but could come from existing NIMH allocations. It should not be taken from existing research on basic brain functions or affective disorders but rather should come from research funds for other mental disorders.

B. NIMH should be returned administratively to the National Institutes of Health so that its primary research function will be developed.

C. Given the expansion of the neurosciences and research on the brain, it is probably time to explore the merging of NIMH with the National Institute of Neurological, Communicative Disorders and Stroke (NINCDS) to create a National Institute of Brain Research. Research on brain diseases such a schizophrenia and bipolar disorder (manic-depressive psychosis) would then be under the same administrative roof as research on brain diseases such as multiple sclerosis, Alzheimer's disease, stroke, and Parkinson's disease.

Stigma: Combatting stigma is a local, state and federal responsibility.

A. A massive educational campaign should be undertaken by the National Institute of Mental Health. Public service announcements should educate the public regarding symptoms, treatment, and what we know about causes of this disease. Such a campaign would be complementary to that begun by the American Mental Health Fund and by the National Alliance for the Mentally Ill.

B. There must be enforcement of federal non-discrimination laws for individuals with schizophrenia seeking housing, jobs, or vocational rehabilitation.

C. Hearings such as these being held today should be held more often. By getting schizophrenia discussed publicly it becomes less mysterious, less frightening, less stigmatized. We see it for what it is - a tragic brain disease, but a disease no less.

Thank you for the opportunity to testify.

Senator WEICKER. I have some questions for you. Let me make a couple of comments relative to your testimony.

First of all, both Dr. Frazier and Dr. Pardes are gentlemen whom I have had the opportunity to work with since I have been chairman.

Really, for a long time, I think that all of those in NIMH, at whatever level, did the best with what they had, especially in the sense of what they had vis-a-vis a commitment from the American people and various administrations.

It isn't a question that schizophrenia was singled out as a subject matter for lack of interest among all diseases. I sit here chairing the appropriations subcommittee that is in charge of a few billion dollars to be applied to the business of life in the United States.

We all sit and cry, as I say, either at the funerals or the bedsides of our friends, for whatever their affliction, and yet when it comes time to go ahead and say, this is going to be a national priority, nobody gives a damn.

If this were a hearing right now on star wars or some sort of a new nuclear device that could blow up the world, the room would be packed with press and people, and the budget reflects that as far as the United States is concerned. It is a direct reflection of what the American people deem to be a priority.

I will say it right here, they don't think schizophrenia is a priority. They don't think cancer, heart disease, Alzheimer's, or AIDS, are a priority. We can all be conservatives, liberals, Democrats, or Republicans, but the budget of the United States is the most unerring, nonphilosophical portrayal of what we deem as a people to be a priority. Those figures don't lie.

I have got to say to you, that having seen the efforts of Dr. Pardes at NIMH, and Dr. Frazier, knowing that they not only have to fight within their own community to get money for the particular projects which they are responsible for, the fault doesn't lie with them, it lies with the American people who, aside from their temporary tears, don't think that this is a priority. In administration after administration, the National Institutes of Health and scientific research are neglected as a matter of our national priorities, with Senators and Congressmen who think it is a lot sexier politically to be out there on defense matters and all the other things such as that, than to be doing the day-to-day, uninteresting business of adequately and consistently funding scientific research. That is the sum total of it.

If this hearing, again, brings to the fore the necessity for that type of a commitment, then the hearing will serve its purpose. But, as I said, I know what a tough road these guys have in front of them over there at NIMH and those that work with and under them, and believe me, there has been a lack of support, where the support should come from.

I want to make that point because I have seen this matter of research sit in the backwater, if you will, of our budgetary priorities, and I think it is wrong. I think it is as wrong as you think it is. I think that the great service is that you are the one that came with Trish, because you are here today to bring this to the attention of the public. Believe me, you are doing your job as a citizen, just as I indicated to Trish.

The final analysis is that as soon as the American people think that their health and their life are just as important as death and destruction, then we are going to be on the right track.

Dr. TORREY. It is a very good point, and let me just add that I think that the 1.6 million families that are affected with this disease are now coming out of the closet. It is now recognized as a brain disease. They are no longer ashamed of it, and they are willing to speak out. I think that they will demand that it be a priority so that your job will be easier, Dr. Frazier's job will be easier.

Senator WEICKER. You are right. This is a difficult thing to say, but you are lucky. You are lucky, you have got 1.5 million people out there who are suffering. I have children coming here with brittle bone disease, or epidermolysis bullosa, where there is only a 1,000 constituency, if you will, and no research money at all.

You are lucky, you have got 1.5 million people. It is the most horrible thing to say that you are lucky, but at least you have got people out there, families out there, that if they apply those numbers, it can translate itself into some sort of action by the Government. All these others, if there are only 15, 20, 100, or 1,000 persons suffering, God help them, somebody better feel sorry for them on this committee otherwise nothing is going to happen. I think that is wrong. I think that is absolutely dead wrong.

I remember when I first became chairman of this subcommittee, and we were on the budget of the Institute for neurological disorders, I had before me the mother of a young man, as a witness, during the public hearings, who had been paralyzed as a result of an automobile accident. Her boy was going to college, and she was pleading for additional research funds.

I remember to this day, and I think those that were on the committee will also remember, she said, "Coincidentally, Senator, as I was waiting to testify I was looking through the budget, the entire budget document." She says, "I notice where there is $100 million set aside for the development of nerve gas, which is the exact amount that I am advocating be added to the Institute."

Then she asked the question, which really is the question that applies to everybody in this Nation, she said, "Why should I pay to paralyze some other mother's son, rather than to unparalyze mine?" That is a damn good question for this Nation.

Senator Proxmire?

Senator PROXMIRE. Thank you very much, Mr. Chairman.

Doctor, I would like to congratulate you on one of the best statements that I have heard before this committee in a long, long time.

Dr. TORREY. Thank you, sir.

Senator PROXMIRE. Your analysis was excellent and you made, I thought, the very impressive and convincing point, that there are alternative ways to spend money in this area. We could take some of that money that we waste and apply it differently. It could be put to far better use.

I also very deeply appreciate your emphasis on the seriousness of schizophrenia, something that I think few of us really understand, and the stigma attached to it. You also gave us a series of specific recommendations, showing precisely how to deal with it, the most useful things that we can have.

I would like to ask you about an inquiry that some of the members of the subcommittee made, in this respect. Senator Inouye, Senator Burdick, and I, wrote to the Director of the National Institutes of Neurological and Communicative Disorders, and Stroke.

We said:

> There seems to be increasing recognition of the probability that schizophrenia is an organic disease of the brain, not completely unrelated to such illnesses as Alzheimer's disease, Huntington's disease, and other neurological disorders.

I thought Dr. Goldstein's response was disappointing. He said, "There is no answer to the hypothesis that schizophrenia may be an organic brain disease," such as Alzheimer's or Huntington's disease, and he went on to refer to the information as being fragmentary and inconclusive.

He said the NINCDS doesn't have a targeted program of research in schizophrenia and that to establish one would mean duplication of efforts already found in the research program of NIMH.

What is your reaction to that?

Dr. TORREY. My reaction is twofold. First of all, I think Dr. Goldstein is wrong. I think the evidence that schizophrenia is a brain disease, is now overwhelming. It has become so over the last decade.

No. 2, we are dealing with the same organ, the brain. Many of the researchers I work with, in fact, are working in NINCDS.

I think Dr. Goldstein's response, if I may interpret for him, is partly the Washington syndrome that you are not supposed to be grasping after other peoples territory. I think that Dr. Goldstein is being a good Federal bureaucrat in not appearing to be grasping.

I think Dr. Goldstein is aware of research enough to know that a great many of the things going on, on schizophrenia research overlap the same things going on in his Institute. As I mentioned, in the 1950's, they had a joint research intramural program. It was all one. I think it should be again.

Senator PROXMIRE. Thank you very much. I appreciate that. I didn't mean to disagree, necessarily, with the main thrust of the chairman's point, which I think is good. All of us subscribe to that, and followed it. I think you point out that there is something else here involved and that the Federal Government should recognize that we can and should do more in the schizophrenia area. Furthermore, we can do so without busting the budget or without an enormous increase in cost. The testimony you and the previous witness made establishes these facts. Thank you.

Dr. TORREY. Thank you very much, sir.

Senator WEICKER. I want to thank you also, Dr. Torrey, along the lines of what Senator Proxmire said.

I have not yet heard from Dr. Frazier and I want to hear from him, and I want to talk to Dr. Goldstein, as well. My inclination is that these things should get together, if you will, that they do no good as a matter of research separate and apart, nor is the public perception that this is something that is separate and apart. I think that both matters really call for trying to get a concerted effort here.

Dr. TORREY. Yes.

Senator WEICKER. Now, as I said, I have not heard from the others, and they may have good reason for indicating that they should stay separate, but certainly my own inclination is that you ought to have one effort, not two.

Dr. TORREY. I would strongly second, sir, the point that you made earlier, that you would decrease the stigma enormously simply by putting the brain disease, schizophrenia, back in with the other brain diseases on the same campus, in the same buildings.

Senator WEICKER. Thank you very much for your testimony, again, and for all that you are doing to bring the matter to public attention. Thank you.

I am going to ask at this time—I know that the witness list has been prepared but I think it would help in the context of comments and dialog, if Dr. Frazier were the next witness.

Dr. Frazier, let me just introduce you to those in the room as being the Director of the National Institute of Mental Health. It is a great pleasure to have you before the committee.

STATEMENT OF DR. SHERVERT FRAZIER, DIRECTOR, NATIONAL INSTITUTE OF MENTAL HEALTH, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Dr. FRAZIER. Thank you, Mr. Chairman. I appreciate having this opportunity to discuss with you and the committee schizophrenia disorders, and the efforts underway at NIMH to stimulate a research program that is really and truly responsive to the personal and family suffering, and to the national economic burden which schizophrenia, as a devastating disease, causes.

There have been a number of historical obstacles to the research in this field throughout this century. The feasibility and pace of research on schizophrenia has been impeded mainly by the lack of access to the brain in the last decade.

We now certainly have the technology and the methodologies for really studying the structure and function of the brain. We, also in the past few decades, had some naive and speculative theories that, I think, often were damaging regarding the origins and the nature of schizophrenia.

I think these theories alienated a lot of patients, and alienated their families. The clinicians and researchers, also, very often, were alienated by the various theories that some had postulated about the causes of schizophrenia.

A lot of researchers were discouraged from devoting their careers to researching schizophrenia simply because it was said to be a disorder that had no breakthrough, no opportunity, and was really a serious problem said to be mainly psychological in its origins.

However, in the recent couple of decades the clinical, scientific, and policy developments have set the stage for what I consider a long overdue reversal of this pessimism, which had kind of been through the field.

After the psychoactive drugs were introduced in 1950, it is pretty clear that there was a biological component to schizophrenia, because the drugs did change the thinking disorder, the hallucinations and delusions, and it quelled a lot of the activity in these patients.

I spent a lot of years of my life on the ward with schizophrenic patients, and I can tell you, when the drugs came along it was entirely different.

I think we also had the opportunity to look at familial components to this disease. Since 1970, there has been rapidly accumulating evidence about brain/nerve chemistry. I think this, with the imaging techniques we now have, has helped us to be able to look at the active, living brain while it is functioning in a live person. I think that has been very helpful in understanding the nature of the thinking disorders and the cognitive disorders.

There has also been at the same time a public awareness of the disease and appreciation of the research advances. In the last two decades, we have seen a large number of schizophrenic patients moved from institutions, hidden essentially.

One out of every two beds in the United States was formerly occupied by a schizophrenic patient. They have been moved out. They have been moved to communities and they have also been deinstitutionalized into the streets, in some instances. There is no question that this was a good movement in one sense, 65 percent of the patients benefited, the other 35 percent didn't, however.

There has certainly been, at the same time, a growing resolve on the part of the families, as well as some former patients, to begin to come out of the closet, to talk about the disorder and to demonstrate themselves as persons who are not out of touch with reality at all times.

I think that is an important thing. From being a permanent disabling disorder, to seem to be sometimes out of touch with reality and at other times in touch with reality. So it has been a big help.

We, in the Institute in the last 1½ years, have been working on a national plan for research on schizophrenia. I think these developments, collectively, will enable the NIMH and the mental health research community to address the task which, I think, has been thwarted and has been viewed also as peripheral to major activities in NIMH.

In 1986 and the years ahead, it is clear that the first and foremost responsibility is to design and carry out a national research initiative on schizophrenia that will be comparable in scale and success to what has happened in cancer. We ought to do it.

Over the past year, we have been assessing the state of our knowledge and the state of the research on schizophrenia. We have begun to bring the people together, researchers.

We had a conference in 1985 on incentives and disincentives to research in the field of schizophrenia. A lot of former investigators, who had worked in the field, had left the field. We asked them to come back and talk about why they left. I think that has been helpful.

At the same time, we have been able to begin to consolidate, conceptually, the very many discreet scientific gains that have been realized in various areas. We have also started a series of consultations with the best researchers in all the brain research. It includes a lot of the people in the Neurological Institute.

I have submitted a major statement to you for this committee. In that testimony, I have described in detail the specific research needs, as this group of consultants and major leaders in the field believe are necessary in the areas of genetics, that includes epidemiological genetics or genealogies in high-risk families, as well as molecular genetics, laboratory-kinds of genetics; also in the area of nerve chemistry, the basic chemical functioning of the brain, localizing certain areas where there are defects or disorders, and then looking at them and also trying to find drugs which, in animals and then later in humans, can alter the defects in these particular areas.

We also have basic research in the area of cognitive neuroscience, that is looking at the thinking disorder, the loss of contact with reality, which is so complex in this disease, with particular emphasis on linking the brain and the inability to get thinking and feeling together in schizophrenia, which is at the base of a lot of the complexity of this disease.

We also are studying brain imaging studies, with the magnetic resonance imaging, with positron emission tomography, PET scanning, now with single photon scanning, and also with brain electrical activity mapping. So we have now some techniques and technologies which allow us to go to the brain of actual patients.

We are also trying to put particular emphasis on treatment studies that are new and novel, treatment techniques, new drugs, how to get patients on low dose to prevent the side effects of the treatment of schizophrenia. There is no question that the movement disorders and the tardive dyskinesia are the biggest problems in the treatment of schizophrenia.

We are also looking at the rehabilitation focus, how we can help these patients, who have been disabled by the disorder, the progressive disorder, to come back through the process of rehabilitation.

It is necessary for us to strengthen the base, the infrastructure of the research community if we are going to make this happen. It means that we have to build some research training so that the young scientists will come into the field in the various centers where we are doing schizophrenia research. That is an important part of it.

It takes from 8 to 10 years to develop a mature researcher, and to bring researchers into the field, we have to attract them. There has to be a predictable response from NIMH and the Federal Government that this is a field that we are going to attend to, so that researchers who decide to move over to this field will stay, stay hooked, and predict that they will have a career here, that something can happen in that possibility of spending their life doing this kind of research.

We need to bring the public and the private research, the universities, the academic establishment, and the State hospitals, where the patients are, to bring these together so we can get the kinds of research subjects we need to get the research done.

The day of single-shot nerve transmitter studies, the day of single-shot imaging, individual kinds of cottage industry research in this disorder, I think that day is over. I think we have to look at large-scale studies, with multiple disciplinary teams of clinical investigators, in the same centers where there are basic scientists, and the subjects have to be looked at over time.

They have to be seen as parts of families. Genealogists have to be tracked down. We have to have the breadth of vision of the grant applicants. We have to also have peer reviewers who understand what we are about. I think then we will have a predictable NIMH policy and the resources to make it happen.

I could go on with a list of research needs for a long time. There is no question at all that we have with this disease a major challenge, as I said, to psychiatry. I have spent a lot of years in this field with lots of patients with schizophrenia. It is very clear this is a disease that sets patients in physical assault, it sets parent against parent with psychological recriminations about having the disorder in the family.

It is also responsible for a large preponderance of the homeless mentally ill who wander our streets and also a number of young chronically disabled, multiple substance abusing, alcoholic-kinds of persons who are in the process of having the disease, the disorder, and also the secondary diagnosis.

It is clear that it has a biological emphasis, a physiological, a psychological, and a behavioral facet. It is one of those complex disorders that brings all of these together. In its complexity, we have to respect it.

I think we have to challenge the invincibility of it, it is a tough illness. I think we need the support from you, this Congress, this administration, we hope to continue our communications with the various advocates and consumers, the people who have the disease and their family members.

We are just beginning to attack that opportunity and obviously we have to connect with the scientists in the field, many of whom are not working on schizophrenia now, but who need to move over and begin to work in this particular area.

PREPARED STATEMENT

Senator WEICKER. Thank you very much, Dr. Frazier. We will insert your statement in its entirety in the record at this point and then go on to some questions.

[The statement follows:]

STATEMENT OF SHERVERT H. FRAZIER

I am Dr. Shervert H. Frazier, Director of the National Institute of Mental Health (NIMH). I appreciate having this opportunity to discuss the schizophrenic disorders--the most complex, debilitating, and, over the lifespan, the most costly of the mental disorders experienced by the citizens of this country.

In this statement, I first will describe the extent and manifestation of the disease. Then I will cite obstacles which have impeded successful research in the past, and, against that backdrop, I will describe the current NIMH schizophrenia research program and our efforts, now underway, to stimulate a significant increase in national research activities aimed at a more comprehensive understanding of the schizophrenic disorders and more effective treatment and care of those with the disease.

Extent of the Problem

An estimated three million Americans will develop schizophrenia during the course of their lifetime. The NIMH Epidemiological Catchment Area study estimates that 1.6 million Americans have the disorder during any six-month period. Although this prevalence is less than that of many other mental or physical disorders, its typical first occurrence in adolescence and young adulthood, its unremitting course after the initial episode in approximately 25- to 30-percent of patients and the persistent recurrence of disabling symptoms in an additional 50 percent of individuals with schizophrenia, combine to make the disease one of the major health challenges confronting the Nation. On any given day, approximately 105,000 patients with schizophrenia are in public mental hospitals; Chart A depicts the distribution, from the perspective of health and human service systems, of adult schizophrenic patients in the population at large.

The annual cost to the Nation of this disorder was estimated in 1977 to be $20 billion dollars of which one-third represented treatment costs and two-thirds represented lost productivity. More recent estimates have more than doubled this amount.

Because of the disorder's complexity, few generalizations hold true for all people who are diagnosed as schizophrenic. To that point, the increasing consensus that the plural, "schizophrenic disorders," may more precisely connote a group of disorders with some common symptoms and multiple causes acknowledges the veritude of Eugen Bleuler's initial identification of "the group of schizophrenias" early in the 20th century.

A major boost to the field of schizophrenia research has been the introduction objective symptoms leading to reliable diagnosis between clinicians and research centers. Although there is not a diagnostic test for schizophrenia--for example, blood tests, brain images, or psychological test batteries--the symptoms described in the Diagnostic and Statistical Manual of Mental Disorders -- Third Edition (DSM--III) published by the American Psychiatric Association are ones which allow for reliable diagnosis.

These criteria include:

- Psychotic symptoms, including delusions, hallucinations, and incoherence;
- Deterioration in role functioning, including social isolation or withdrawal, poor personal hygiene, and peculiar behavior;
- Duration of symptoms for a period of at least 6 months;
- Age of onset of symptoms constituting the diagnosis of schizophrenia prior to 45 years of age;

- Full manic or depressive symptoms either absent, subordinate to the psychotic symptoms described above, or relatively brief in duration;
- Exclusion of organic brain disorder as the cause of symptoms.

These diagnostic criteria will continue to evolve and be refined in the near future as increasingly sophisticated methods of brain research are applied to the study of schizophrenia and, comparatively, to other major mental disorders. In the interim, scientific dissent over the boundaries of the concept of schizophrenia is neither academic nor trivial. Rather, it reflects an increasing resolve on the part of the clinical research community to define core features of the disorder, thus ensuring appropriate treatment of the disorder in treatment settings and recruitment of comparable patient samples for research, as well as accurate interpretation of research results.

Obstacles to Research

Throughout this century, numerous discrete obstacles have impeded both the feasibility and pace of research on schizophrenia; the collective impact of these has been evident not only in the scientific realm, but also in the public demand for increased support of research on the disease.

Early confidence that a lesion, or physical aberration, in the brain would be identified was thwarted by the inaccessibility of the brain *in vivo* and, in post-mortem tissue, by the subtlety of physical abnormalities which may have contributed to the phenomenology of the disorder. In the absence of an identifiable pathophysiology, theories regarding the origins and causes of the disease placed heavy emphasis on its occurrence as a reaction to psychological or environmental stressors. While such theories accurately reflected the etiologic assumptions built into the earlier versions of the U.S. diagnostic system, an effect was to drive a wedge between researchers and clinicians, on the one hand, and potential advocates and collaborators in research, on the other. Seen by some members of the clinical and research communities as a "cause" of the disorder, family members often were not encouraged to serve as a positive source of assistance in devising more effective means of caring for patients with schizophrenia.

Yet another key reason for the lag in research on schizophrenia is traceable to the origins of modern psychiatry as a hospital-based, administrative profession in contrast to the university-based, scientific tradition of other medical specialties. Prior to the 1960s, large numbers of schizophrenic patients were hospitalized in public mental hospitals, settings in which little research was conducted and which were inadequately, if at all, linked to academic settings. Not until the 1950s and 1960s, following the establishment of NIMH in 1946, did the orientation of American psychiatry and the related mental health disciplines turn more fully toward rigorous fundamental science and clinical research. In the 1970s the trend toward deinstitutionalization created another problem: that is, even as mental health research capacities were increasing in university settings across the country, a diversified system of care made it increasingly difficult for academic researchers to gain access to groups of patients with schizophrenia who were viable research subjects.

Finally, a critical obstacle to research over the years has been the inadequacy of the research manpower base committed to intensive, long-term study of the schizophrenic disorders. Even with the emergence of a scientific psychiatry, a firmly entrenched nihilism regarding schizophrenia and its prognosis served to discourage many investigators from choosing to devote their careers to the study of schizophrenia. This nihilism reflected the limitations exerted by the nature of the disease on the ability of patients to participate in research, and the more immediate opportunities for research yield in the study of other major mental disorders such as, for example, the affective disorders.

All of the factors cited above, exacerbated by misunderstanding, fear, and stigmatization of a complex psychiatric disorder have served to discourage public and political support and interest in a sufficiently intensive, sustained research program targeted on the schizophrenic disorders. This was reflected in the proportion of the NIMH research budget dedicated to studies of schizophrenia.

What Has Been Accomplished

In recent decades, these longstanding obstacles to research on schizophrenia have gained increasing recognition and all have begun to be addressed. Listed briefly below are selected developments and accomplishments which enhance significantly the feasibility of a major national schizophrenia research initiative.

Fundamental to the current feasibility is the combined yield of basic and clinical research conducted in all areas of mental illness and health over the past several decades. In the 1950s, evidence that the major mental disorders were responsive to pharmacologic treatment underscored the contributions of biological factors to disorders which theretofore had been viewed largely as characterological flaws or stress reactions, and suggested new directions for research.

In the 1960s, landmark studies advanced the genetic hypothesis of schizophrenia by demonstrating in sophisticated studies that rates of schizophrenia were high in the offspring of schizophrenic parents, even when reared apart from their families. Various investigators, all aiming to separate genetic from environmental factors, demonstrated the genetic underpinning of schizophrenia, thus providing the essential framework for genetic studies to be described below.

Also in the 1960s, scientists began to understand the important mechanisms by which nerves communicate--through chemical messengers called neurotransmitters. As neurotransmitter theories were postulated for schizophrenia, there was a tremendous increase in scientific studies focused on the chemical messenger, dopamine. Such research has lead to important recent findings, including increased dopamine receptors in the brains of schizophrenic patients and the usefulness of measuring dopamine metabolites in the blood of patients.

One of the barriers to schizophrenia research in the past was the skull. Unlike other more accessible organ systems, the brain sits in a bony cavity which made traditional X-rays uninformative. Within the past decade, new brain imaging techniques such as Computerized Axial Tomography (CT), Positron Emission Tomography (PET), Magnetic Resonance Imaging (MRI), and measurement of regional cerebral blood flow (rCBF), have made possible productive studies of both the anatomic structure and, subsequently, the neurophysiologic function of the brain. These technologies dramatically reinvigorated research on the biological aspects of schizophrenia, and encouraged investigators to appraise critically and discard earlier speculative and often damaging theories regarding the etiology of the disorder.

While all of these and other developments were occurring on largely separate paths, there emerged in the late 1970s a new national organization—the National Alliance for the Mentally Ill--which has served both to crystallize the attention of the research and clinical communities to the specific challenges posed by schizophrenia and to encourage increased public and legislative attention to the needs of the severely mentally ill.

Finally, the continuing realignment of Federal and State, public and private roles in the administration and management of mental health service systems has made increasingly clear the need for more effective collaboration among all of these entities in the support and conduct of research on the major mental illnesses. We are seeing growing acknowledgement, for example, of the need for better links between university-based research programs and public mental hospitals where potential clinical research populations reside. Also, a growing number of States are recognizing a need to expand research capacities within public settings, both to address immediate service system questions and to complement Federal research support.

Establishing an Administrative and Conceptual Base

Given these developments, efforts of NIMH over the past year have focused in large part on expanding and strengthening our capacity to mount a major schizophrenia initiative.

A first need was for an NIMH organizational structure that clarifies lines of responsibility and accountability throughout the Institute, and that allows incisive targeting of resources to clearly delineated needs. This has been accomplished.

A key feature of the reorganization in 1985 was the reconfiguration and expansion of the Schizophrenia Research Branch, the NIMH component responsible for administration of extramural, or grant-supported research. Over the past year, we have more than doubled the staffing of this program and, as noted below, substantially increased fiscal resources available for its support of programmatic priorities.

Within the NIMH Division of Intramural Research Programs, we created a new Clinical Brain Disorders Branch, the primary focus of which will be studies of schizophrenia and Alzheimer's disease. At present, of the 100 clinical research beds maintained by the Intramural Research Program, approximately 50 are devoted to research involving patients with schizophrenia, far more than to any other disorder.

We also recognized the need for expansion of the cadre of researchers focusing their efforts on schizophrenia. In July, 1985, NIMH convened a working group of leading scientists to discuss disincentives to the choice of a research career in schizophrenia and to recommend means of attracting scientists to the field. A report of that meeting, including recommendations made to the Institute, appears in the Spring, 1986 issue of Schizophrenia Bulletin.

Throughout the past year, we have worked intensively to assess the state of our knowledge in schizophrenia. In May, in response to a recommendation of the National Advisory Mental Health Council's Committee on Schizophrenia Research, members of the Schizophrenia Research Branch presented its grants portfolio to the Advisory Council. In June, a two-day session of the NIMH Extramural Scientific Advisory Board was dedicated to yet another review of our program and of the field.

With this and other consultation, we have begun to consolidate, conceptually, the many discrete scientific gains that have been realized in recent decades and have begun to plan a national schizophrenia research agenda.

Developments in 1986

The intensification of our commitment to schizophrenia already is evident. Between fiscal year 1985 and 1986, in the Division of Clinical Research alone, NIMH achieved a firm 19 percent increase in funds targeted directly on schizophrenia.

The largest portion of the increase is attributable to awards made to fund two new Clinical Research Centers focused exclusively on schizophrenia. While several of the 13 Clinical Research Centers supported by NIMH devote a portion of their research to schizophrenia only one exclusively schizophrenia-focused Center existed in the United States in 1985. This was--and remains--at the University of California at Los Angeles, under the direction of Robert Liberman. With the addition this year of Centers at the University of Maryland, headed by William Carpenter, and at Long Island Jewish Hillside Hospital, under John Kane, the NIMH investment in Schizophrenia Research Centers has increased by more than 110-percent.

We have increased by one-third over last year's level the number of Research Scientist Development Awards made to investigators working in areas clearly and specifically relevant to schizophrenia. We expect another significant increase in Research Scientist Development Awards in FY 1987.

Investigator-initiated, schizophrenia-specific awards increased this year by more than 12 percent in the Schizophrenia Research Branch and

13 percent in the Epidemiology and Psychopathology Research Branch; the latter reflects an award to investigators at the University of Maryland for clinical research involving a large, community-based sample of schizophrenic patients in Baltimore.

Strategies and Directions for 1987 and Beyond

In this section, I will describe, first, the strategies which we intend to employ in strengthening the schizophrenia research program and, second, suggest specific areas where immediate stimulation looks most promising.

With regard to research personnel, verbal inducements alone will not attract the bright young minds--or the bright older minds--that the future of schizophrenia research is hinged on. We must support the Clinical Research Centers (CRC) and other new, innovative Centers of Excellence at a level--and at a level of stability--that will assure people that they are not turning onto a career path that will fade out a few years from now.

The degree of basic-clinical research interaction, the intellectual ferment, and the research training opportunities that exist or are possible in a large Center or program project site are unattainable elsewhere. But the dynamics can be precarious. People gravitate to the mass, and if the mass deteriorates, people are going to slip away. By augmenting CRCs and program project grants with research and research training dollars, we will send a clear message to the field that the emphasis that NIMH now is placing on schizophrenia is buttressed by a longterm commitment. We are encouraging Clinical Research Centers to take on major responsibilities as trainings sites for future generations of scientists.

Even as we fund such Centers, we realize, as do scientists in the field, that one support mechanism cannot carry an entire field. A research program, whatever its size, is comprised of individuals pursuing their own careers, and those careers require support. At NIMH, ADAMHA, and NIH, the entire existing array of career support mechanisms are undergoing intense scrutiny. We are assessing the potential benefits of developing new career support mechanisms which will enable young persons to embark on research careers as well as to extend support of established, senior investigators who are engaged in highly significant projects.

Given that we will address the personnel problem, we then must A) demonstrate our firm commitment to the investigator-initiated, peer committee/Council review process and B) having established that commitment, make every attempt to fund all high-priority schizophrenia and neuroscience applications at Council-recommended amounts. When we demonstrate our commitment to maintaining the integrity of the system, I predict that we not only will be paying high quality applications at appropriate levels, but that we will demonstrate our commitment to expanding the field as well.

That, finally, raises the question of what specific areas ought we to be stimulating, given current and anticipated levels of resources? As I noted earlier, we have sought and received a good deal of expert consultation over the past year, and we are going to act on it.

With the advice and consultation I described earlier, NIMH has identified 6 areas crucial to a comprehensive and sustained research initiative focused on schizophrenia. These areas are listed and described below.

I. Brain Imaging

Recently developed brain imaging technologies have presented us with new opportunities for investigating the pathophysiology, treatment and etiology of schizophrenia. These techniques include positron emission tomography (PET), single photon emission tomography (SPECT), and nuclear magnetic resonance (MRI).

Pathophysiological studies employing PET scans have already demonstrated abnormal patterns of brain metabolism in the frontal cortex of patients with schizophrenia. In addition to such anatomical studies of brain activity in response to complex tasks, PET scans can be used to map the functioning of a specific neurotransmitter pathway involved in this activity. To accomplish this task, new tracer methods must be developed. Other areas of application are the study of functional anatomical response to pharmacologic challenges and longitudinal studies of patients.

Imaging techniques may also be used to study the functional anatomy and neurochemistry of patients before and after treatment. These studies would shed light on treatment responsivity, dosage requirements, and side effects because they permit researchers to see where the drugs work in the brain.

Imaging studies are also likely to provide new clues to the etiology of schizophrenia, particularly in determining homogeneous subpopulations of patients. Studies of high risk populations should prove useful in identifying the genetic and developmental aspects of schizophrenia.

II. Genetics:

Recent advances in genetic epidemiology and molecular genetics make it possible to initiate studies on a large scale that could uncover the neurogenetic basis of schizophrenia and other major psychiatric disorders. These advances include standardized interview methods for reliably assessing both psychotic symptoms as well as non-psychotic variants that are related to schizophrenia; quantitative methods for identifying clinical subtypes that differ in inheritance patterns, and quantitative methods of pedigree analysis that permit investigators to take into account incomplete penetrance, variable clinical severity, assortative mating, and a variety of environmental and sociocultural influences on familial transmission. In addition, the map of the human genome recently has been improved greatly using molecular genetic techniques that present the possibility of identifying heritable gene markers. Finally, sufficient quantities of tissue are available to obtain nucleated cells (lymphocytes) that can be immortalized in culture, providing a dependable source of DNA and living cells for molecular biological studies. Such tissue cultures permit studies that are not influenced by drug treatment of the patients and their relatives.

To take advantage of these advances in genetic research on schizophrenia will require stable, large-scale support. The extensive clinical heterogeneity observed in schizophrenia is probably matched by a comparable genetic heterogeneity. The delayed age of onset of schizophrenia requires that family members be followed for many years. In addition, because schizophrenia is associated with incomplete penetrance and reduced fertility, the most typical cases rarely have large families with many affected individuals in successive generations. This means a large number of families must be included in studies of pedigree structures.

These requirements indicate the need for stable, multifaceted research centers that permit psychiatrists, epidemiologists, neurobiologists, and molecular biologists to work together on studies of the genetics of schizophrenia. This is in marked contrast to the situation with rare Mendelizing disorders such as Huntington's disease where progress can be made at the molecular biological level alone once the family is ascertained and cell lines established. In such disorders, all cases are expected to have the same cause, but this cannot be assumed for schizophrenia and other major mental disorders.

III. Neurochemistry:

Research on the chemical substances involved in the communication between nerve cells is central to the fight against schizophrenia. These compounds are termed neuroregulators and function either as neurotransmitters between nerve cells or as neuromodulators which alter the effects of neurotransmitters. Until recently, we thought that we knew the identity of all the substances which act as neuroregulators. Now, we know that there are many others. As they are discovered, their chemical structure must be determined, their formation and effects on receptors studied, their localization in the brain identified, their gene regulation investigated, their development outlined, and their relation to behavior investigated. This emerging complexity also introduces the problem of determining how these different neuroregulators interact with each other.

Three other problems require attention. First, we need a better understanding of the developmental changes that occur in different neurochemical systems involving neuroregulators. Schizophrenia frequently strikes in late adolescence or early adulthood. Other severe forms of mental illness are associated with different stages of the life cycle. Second, we need to know more about the effect behavior has on biochemistry as well as the impact biochemistry has on behavior. The fact that behavior can impact on biochemistry may provide us with a better understanding of the role of developmental and environmental influences on severe disorders. Through such understanding we may be able to more effectively integrate pharmacological and psychosocial therapies. Third, we need to examine the possibility that the cause of schizophrenia (or at least some cases of schizophrenia) involves a virus and/or an abnormal gene disrupting the normal cellular function of the central nervous system. The viral hypothesis is compatible with other theories of schizophrenia, in particular those focusing on genetic transmission and on catecholaminergic abnormalities. It is known that there may be a genetic susceptibility to some infectious diseases and that viruses themselves may be transmitted intergenerationally. Moreover, animal research has shown the ability of a virus to affect monoamine metabolism. Furthermore, recent research has demonstrated that viruses may have subtle cellular and molecular effects, altering gene expression and metabolic processes rather than simply killing the host cell.

IV. Cognitive Neurosciences:

The field of cognitive neuroscience, a discipline devoted to the quantifying the relationship between brain and behavior, has grown dramatically in recent years. Research in neuropsychology suggests that it is possible to combine leads about schizophrenia that come from careful detailed experimental studies of performance with those that come from studies of the functioning of specific brain areas.

Exciting leads in schizophrenia research already have been found by linking the performance of patients on standardized batteries with other tasks of brain functioning. For instance, schizophrenics are similar to patients with left frontal lesions in showing much less of the electrical activity normally associated with attending to a source of sensory information. In addition, a study of acute never-medicated schizophrenics engaged in a task involving a shift of attention from one dimension of a stimulus to another showed evidence of an abnormality in the dorsolateral prefrontal cortex.

A few years ago this knowledge at the performance level would have provided few clues as to the underlying neural systems that might be responsible. However, much has changed in the last few years. First, we have many more explicit methods for careful, time-locked measurements of attentional function including alertness, memory selection, semantic selection, and conflict. Second, we are starting to identify the neural system that forms the basis of normal selective attention. Third, we have new methods of neural imaging and electrical and magnetic recording that provide a basis for the further exploration of the relationship between neural systems and attention.

V. Clinical Diagnostic Strategies:

Three areas concerning the diagnosis and phenomenology of schizophrenia need intensified research. First, we need to look at the heterogeneity of schizophrenia. We need typologies that maximize heterogeneity between diagnoses and homogeneity within groups. Construction of such typologies will require a substantial investment in development of new assessment instruments. As we improve our ability to identify homogeneous and discrete disease categories, we will improve our ability to identify their mechanisms and causes and to develop improved methods for treating or preventing them.

Second, we must discover and confirm those traits associated with schizophrenia-proneness. The standardized methods for clinical description currently available must be broadened to provide a more thorough and comprehensive data base. This data base must be broadened to include the many domains known to be related to schizophrenia as well as such nonsymptom characteristics as attentional dysfunction, low IQ and other abnormal psychological test performances, smooth pursuit eye movement errors, brain abnormalities, and suicide. Although suicide is generally associated with depression, the suicide rate among schizophrenics is clearly higher than in the general population.

Third, we need to determine where the various psychoses stand in relation to schizophrenia. This quest is part of the larger task of defining the boundaries among schizophrenia, other abnormalities, and normality. Such definition is necessary because certain personality disorders other than schizophrenia occur with increased frequency in relatives of schizophrenic individuals.

VI. Treatment:

Several efforts need to be pursued in treatment research on schizophrenia. One major goal is the development of new medications that effectively treat negative as well as positive symptoms and that have fewer and less severe side effects. The development of drugs which act in new ways, not just blocking dopamine receptors, is one starting point.

There is also a critical need for clinical trials involving patients who do not respond adequately to antipsychotic medication. These trials will require the development of reliable criteria for categorizing such patients and multi-center sites to achieve sufficient sample size. Another effort should be directed at testing the preclinical leads which suggest specific drug combinations to reduce the risk of tardive dyskinesia. About 15 percent of patients receiving neuroleptic treatment over an extended period of time develop this condition. Women and the elderly are especially susceptible. Efforts to reduce the incidence of tardive dyskinesia through the use of low dose and intermittent medication strategies will continue to be evaluated.

In addition, much more remains to be learned about the specific indications for and effects of various pharmacologic and psychosocial therapies, particularly in different subtypes of patients and at different phases of the illness. Rehabilitation must become an integral part of any treatment strategy. Rehabilitation efforts must be matched to the different stages of the disease and aimed at achieving an independently functioning individual.

If progress is to be made in treatment response, however, large cohorts of patients must be assessed on biologic, neuroradiologic, genetic, and psychosocial predictors and treated in a controlled, systematic fashion to relate those factors to treatment response. This should be done as early in the illness as possible because treatment response may change over the course of the illness.

The development of successful treatment and rehabilitation strategies, however, does not entirely solve the problem. There still remains the complex task of integrating these strategies into the health care system to insure the effective and efficient delivery of services to the mentally ill, particularly the chronically mentally ill. Achieving this objective will require a major expansion of services research related to the financing of care, the organization and delivery of care, and the assessments of treatments for the mentally ill in service settings both in the hospital and the community.

In advancing our knowledge about the etiology, diagnosis, and treatment of schizophrenia, this major research initiative should reduce the stigma and fear attached to the illness. Borne of ignorance, this stigma has significantly increased the burden this disease inflicts on its victims and their families. By demonstrating the etiological and biological basis of schizophrenia, we can do much to enlighten the victims of this illness, their families and the public and hence reduce the fear and ignorance attached to this illness. By developing effective treatments we can further reduce both the dread and the fear associated with this disease.

I appreciate this opportunity to comment on our activites and our plans for the future. I would be pleased to respond to any of your questions.

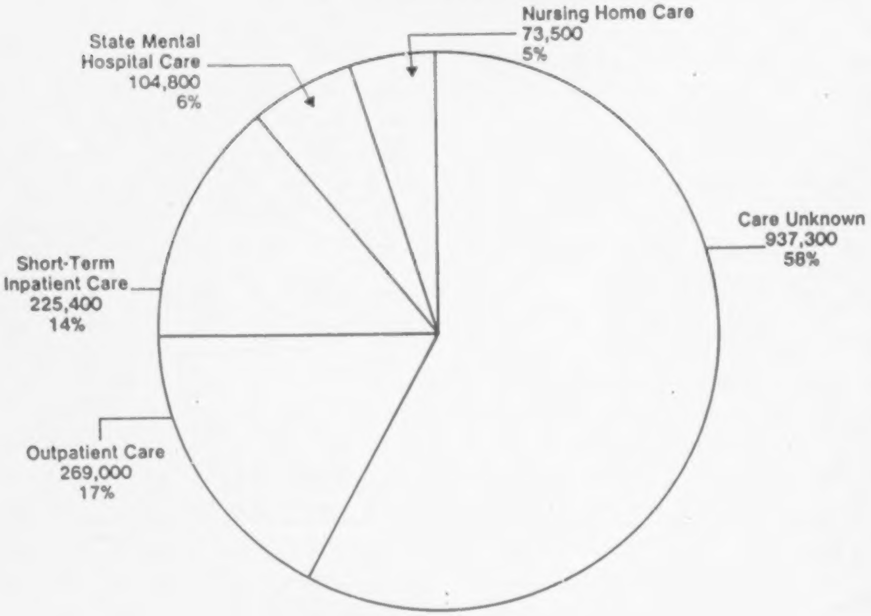

CHART A

Distribution of Adult Schizophrenics in the United States
(N = 1,600,000)

Senator WEICKER. Let me just, if I may, elaborate on one point that you made in order that those that are viewing the proceedings may understand. I think it is a key point.

In order for you to get what you need in the way of researchers, you not only need more dollars, but just as importantly, there has to be a consistent commitment.

If we go through our national budgetary fads, and go up and down, up and down, nobody is going to want to get into the field. They will figure, fine, I am hired for this year and next, but then I don't know what is going to happen in the third and fourth year.

This applies right across the board, I might add, in terms of research. That is why dollars, No. 1, should be high, but they should also be consistent insofar as our priorities are concerned.

Point No. 2, please comment, if you will, on what seems to be a very logical idea to many of us, and obviously has been advocated at least by one witness, that this be consolidated into one effort. There has been the National Institute of Mental Health out there separate and apart from NIH, including the Neurological Institute, et cetera. Why shouldn't this all be under one umbrella?

Dr. FRAZIER. There is not any question that the brain is the organ involved. It is the focus of the researchers, and it is very clear that there are different kinds of brain researchers.

I have worked in laboratories with neurologists, as well as with psychiatrists. It is very clear that there are common interests. There is also a focus on behavior in schizophrenia, where many brain researchers are not qualified nor able, by their training and their experience, to do adequate research.

So behavioral research, the behavioral components, and the thinking components, the cognitive components, are not really usually addressed by neurologists. That is not to say they shouldn't. It is just to say that the basic differences in these departments and medical schools are historical perceptions of what the specialty was at a given time and space. It doesn't mean that they are holy or endowed forever, it just means that they happened to be historical antecedents of where we are now.

It is also clear that we have worked for a long time in NIMH with the scientists at NINCDS, and we still do. Many of the senior scientists at NINCDS were trained in NIMH, so it is very clear that that has been a source of a lot of responsible training. That means that those people know about behavior, many of them do.

We have joint funding of brain banks. Presently, NINCDS and NIMH jointly fund the various brain banks where we collect the brains from the patients that have these disorders with the clinical histories, so that we can go back and study the cells under the electron microscope and do immunohistochemical fluoro-staining, selective staining, of these various cells in the brain tissues, which have been saved in these brain banks.

We also have common studies in brain imaging. The positron emission tomography, the PET scanner was developed at NIMH. It is now jointly involved with both the institutes involved with the brain and brain research. It is also clear that the intramural research program at NIMH has coinvestigated many neurotransmitters with NINCDS scientists.

We jointly funded in the past the neuroscience's research program at MIT, Massachusetts Institute of Technology, Frank Smith's program. That was a joint venture, and probably the single most successful beginning. The counted keystone to the burgeoning neuroscientific tradition, was the joint funding by both these institutes of the neuroscience's research program at MIT.

Senator WEICKER. Let me bring it down to a very pragmatic hypothetical. Let's say that as a result of this hearing, we are able to convince our colleagues on the committee that a greater emphasis should be placed in the 1988 budget on schizophrenia.

How would you advocate that those additional funds, whatever they happen to be, be divided up? Should more go to the Neurological Institute, or should more go to NIMH?

Dr. FRAZIER. I am not wise enough to know how funds are appropriated in the first place. I usually am the recipient of a piece of paper that says you have got so much, with a lot of directions about how I should follow it.

Senator WEICKER. I understand. I will attest to that. I think the people in the United States should know that most of the research and scientific budgets of this Government are devised not by the researchers and the scientists and the doctors, but by a bunch of anonymous people over at the Office of Management and Budget, many of whom probably didn't get through college. They are a bunch of flakes. [Laughter.]

So I am well aware as to what you are talking about as far as directions are concerned.

What I was trying to say to you, Dr. Frazier, is that I am trying to do a job here on the Appropriations Committee, and it would be easy if, indeed, there was one entity in which to place the money, but there is not. There is NIMH and there is the Neurological Institute.

I am just wondering how I could perform properly in the sense of trying to get at this problem in the fastest, most direct way. Where should the emphasis be placed? The emphasis right now, I would assume, more or less sits over at NIMH.

Dr. FRAZIER. Yes.

Senator WEICKER. But isn't it true since NIMH was set aside as a separate Institute that we have come to learn that many of these matters are related to bodily changes, chemicals in the body, et cetera? That more or less falls into the part of the Neurological Institute.

Dr. FRAZIER. There is no question that in the development of the science, we have moved more toward the basic neurosciences and the biological sciences, and our allocations of funds within the Institute has moved to the biological side from 1980 to 1987 a considerable amount.

It is pretty clear that having funds in the neurosciences makes a lot of sense if it could be somewhat conjoint. However, it is very clear that as long as we are in separate agencies it makes a difference.

It is also clear that programatically we are in different locations as far as the extramural programs are concerned. The intramural programs are on the same campus and do work together much better than the extramural programs, no question about that.

It is also clear that when you take scientists, research scientists, who are in the same tradition and many times from the same laboratories, who are people of goodwill, that they indeed will work together given that impetus and also that focus. I think that is a reasonable way to go pending organizational changes.

Senator WEICKER. Let me ask you to do this, and I am not asking you for an immediate response, and I assure you that I intend to keep communication at the utmost—presupposing there is going to be a special effort made on schizophrenia in the next budget.

Dr. FRAZIER. Yes.

Senator WEICKER. I think that is a safe bet.

Dr. FRAZIER. Yes.

Senator WEICKER. Will it be possible, by the time that we come to the regular appropriations hearings, to hear from you and Dr. Goldstein on some formal mechanism, in other words, that would coordinate to an even greater extent than the examples that you have given on these extra funds, assuming that we don't get structural change—and that usually does take a couple of years and this is something I don't think we want to wait on—would there be some form of mechanism between the two of you that you could guarantee a cross-pollination of that effort.

Dr. FRAZIER. You can depend on it.

Senator WEICKER. We have been joined at the hearing by the individual in the U.S. Senate who has brought a focus on schizophrenia. I don't mind saying that from time to time each one of us is affected, either by family or by a friend, and we tend to put a little more emphasis on a particular area that comes before the committee.

Sometimes things get left aside and I think that was the case here. I will be the first one to admit I didn't really focus on this problem until it was brought to my attention by Senator Domenici, and then by Trish.

Senator Domenici of New Mexico has just joined us. I think it is to his great credit that the additional funding that has been included in the last Federal budget is a direct result of his efforts.

Senator DOMENICI. Thank you Mr. Chairman. I really don't believe those statements are all that true, but I can't take them off the record so I thank you for them.

Let me say, however, that I do believe we can do better as a nation than we have done in the past. I have talked to enough of the people that are involved that I have a few things that I would like to discuss.

First, I do not believe that the fact that we have not done as well as we should have in the last decade on the terrible illness of schizophrenia is because we don't have dedicated people. I don't think that is the case at all. I don't think it is because the medical profession and the scientists are unaware.

I think, basically, what has happened is that through our institutes that focus on that illness, we, basically, have not put together a framework which has two or three ingredients; one that pulls the resources together in a better way and one that builds in some continuity, some assurance.

You are not going to get the greatest young talent in this country and research teams to involve themselves in this kind of a research project if they do not believe that there is a future. You have got to get the young talent early on when they are excited and enthusiastic, and they have to look out there at the country and say somebody wants us and somebody really expects us to be involved for a few years. We can, through this mechanism that you have been discussing pool the resources so that they can be focused. If Congress can then speak to the issue without necessarily any radical changes, but perhaps some changes in the institutional structure, there are enough of us around to develop a framework and a focus. I think between us we can do that.

The other comment that I want to make is that I think we have reached the point where there is no fear about making this very public. Some of the groups in our country, NAMI and others, have taken the lead in making this an on-the-table issue just like cancer or anything else; there is no longer any stigma attached.

It is a very, very serious American disease and illness. It ought to be addressed that way and I think we are, don't you, doctor, we are pretty close to that?

Dr. FRAZIER. Yes; we are, thankfully.

Senator DOMENICI. People are talking about it, and people that have had the problem are very willing to get up and talk about it just like anybody else that has had some major illness. I think that is a giant step in the right direction.

Last but not least, Mr. Chairman, I believe there is a very, very large group of American people that want to help us help solve this problem. I don't think that is anything to be made light of, when you look at the thousands of Americans who are now in one or two of the major support organizations.

We are really saying we are there to help, and we want to help you if you need help in the Congress. I think that is a giant step in the right direction. That means that there are a lot of suffering people, and they are not only the ones with the illness. You have families, and close relatives who are now joining in this huge kind of almost an army, saying we want help and we want to be helpful. I think that will make a difference.

I want to compliment the national institutes that are involved, the National Institute of Mental Health and the others. I think that they have always been concerned, but I think they needed us. They needed public support, and they are getting it. I think they will do a much better job as a result, and they will respond.

I intend, from my standpoint, if I am in a position to do so here in the Senate, to continue to try to be helpful. At one point, I thought we ought to reform the whole thing and start over with a new institute. That is the fever of a novice, I guess. We do have a lot of good institutional thrusts, but I still believe we have to do some reforming so that there is more of a focus on schizophrenia, more continuity of effort, and more accountability. If we can work on that together, I think it would be very exciting.

I also think there is a change in attitude, Mr. Chairman, about those who are treating the seriously mentally ill, including those with schizophrenia and other mental illnesses. I think professionals in the field are also beginning to understand that this is not just a patient problem. I think they are beginning to understand that it is a family problem, that everybody needs to be helped. You can't hide out in the back room and cure their illnesses; the ill person needs help, and those who want to help need to be involved. I think that is changing dramatically. That change is a little slower from the standpoint of American psychiatrists, I believe, but I think they are beginning to change too. That is necessary.

We can't do that, Mr. Chairman, but they can. Groups of Americans can, and I think they are beginning to respond a little more in that regard, so I compliment you for the hearing today.

Obviously, this is an exceptional hearing. The time of year didn't demand this kind of hearing or even justify it, but because of your genuine interest in getting things started early, you are here and a lot of people are here. I compliment you for that. Thank you very much.

Senator **WEICKER**. Thank you, Senator Domenici. Thank you very much, Dr. Frazier.

Dr. **FRAZIER**. Thank you very much.

STATEMENT OF JOSEPH A. ROGERS, CHAIRPERSON, NATIONAL MENTAL HEALTH CONSUMERS' ASSOCIATION

Senator **WEICKER**. Our next witness is Joseph Rogers, the chairperson of the National Mental Health Consumers' Association, a coalition of self-help groups for the mentally ill.

The association's efforts are targeted toward protecting the rights of the mentally ill, fighting discrimination in housing and employment, advocating for consumer representation on mental health decisionmaking entities, and fighting the stigma associated with mental illness through public education efforts.

Welcome, Mr. Rogers, to the hearing and we are pleased to see you.

Mr. **ROGERS**. Senator Weicker and Senator Domenici, I want to send greetings from two self-help groups, the Catalyst for Change Group in Torrington, CT, which is a very active rights protection group in Connecticut, that is now very active with the protection and advocacy system. I want to send greetings from Channel One in New Mexico, which is a strong group, active in New Mexico, developing self-help and mutual support for present and former mental patients in New Mexico, and also from Marcia Lovejoy, who is active in training mental patients, a former mental patient herself, diagnosed schizophrenic, who is doing work to train consumers' in self-help activities.

I want to also take this opportunity to kind of personally thank Senator Weicker for myself and many others of the mental health consumers. I never thought when I was locked away in a ward, having suffered from abuse in a State hospital situation, that I would be here and able to thank somebody for what you have done in terms of helping to develop a protection and advocacy system nationally.

If you ever want to run for President, Senator Weicker, you have got the mental patient vote. [Laughter.]

Senator PROXMIRE. Don't say anything, think for a while.

Senator WEICKER. I would be honored; that is the way I would like to respond to that.

Mr. ROGERS. You definitely have our vote, and this hearing, I think, even furthers it.

It is amazing, even in the last week, the amount of energy and interest in our situation. I have been struggling since I was first hospitalized at 19, now for 15, 16 years, in terms of talking about this illness and trying to get people to recognize that there is a problem. Even working just with consumers and families to have them feel comfortable with who they are as individuals.

In this hearing, one of the issues is stigma. The reason that it is so hard for consumers to talk about their illness, even among other consumers, is that there is a massive stigma. There is an attitude that prevails, and purveyed all of our thinking in terms of mental illness that is very negative.

You asked earlier in terms of why people aren't interested in this illness or why there seems to be a difficulty. I think part of the problem is that it is almost a moral burden, that we as ex-patients and present patients face in terms of the term "mad is bad," in that suffering from this illness there is a cause that we are blamed, and the family members are blamed for.

What are we doing about that? I think this hearing is an example of something that we can do about it, begin to discuss these vital issues in terms of research and programs.

What we are doing as a consumer movement is to begin to organize present and former mental patients to begin to speak out. This is really a recent occurrence in the last few years, people like Marcia Lovejoy in New Mexico, and people like Judy Chamberlain and other folks who have suffered from mental illness began to speak out and talk about their mental illness.

More recently, I have had the opportunity to be able to speak in about 30 States as chairperson of the National Mental Health Consumers' Association, also as associate director of the Mental Health Association in southeastern Pennsylvania. We have begun to be able to reach out and organize programs of community education that involve the consumer and involve the family member.

Not only are we educating the community, but we are educating professionals so that professionals become more responsive and view the consumer as somebody who can work in partnership, and the family members who can work in partnership in overcoming mental illness.

The issue that I think that we have concentrated so far in this hearing on research is one. As I talk to mental health consumers around the country, it kind of boils down to this. I remember when I first was coming out of the hospital. I met with my doctor in an outpatient program and he sat down and we talked.

I had been basically through hell and had come out and now was able to sit down and talk. Before I went into the hospital I couldn't talk to anybody. The medications had helped and had calmed me down and allowed me to communicate with this doctor.

I asked the doctor three questions. I asked the doctor, basically, what happened to me? I mean it is sort of like somebody who is hit by a truck and they ask well what is the license plate of the truck. What was this that happened to me? I asked the doctor, well what can be done for it? What treatment is there? The third question, what is my future? What is my future in terms of what this illness will do to me in the future?

At that time, 15 years ago, the doctor's answer was we really don't know on all three questions. Unfortunately, for myself and other mental health consumers still suffering from this illness, that is still the answer. They go to their doctors and they ask those three questions and that is still the answer.

So we really don't know what causes the illness. We really don't know too much what to do for you. We can provide some programs, and definitely that is an area that has been improved and I thank this committee for its support of the community support program at the National Institute of Mental Health. It has made a massive difference in my State and States like Ohio, and I believe in Connecticut, in terms of coordinating services and making the State aware of its responsibility and helping States coordinate their services to this population.

The third question is, what is our future, and 15 years later we still don't know the answer to that question. Our only real hope is research in that sense. Our only real hope is to find and develop a real scientific understanding of this illness.

I support the idea and for more money for research, for better coordination of research, a greater commitment in terms of the National Institute of Mental Health toward research in this major area. We need to continue, though, in addition to the research the development of the programs. They still need a Federal coordinated effort.

I have a chance to travel around the country and there are still many, many States that have failed to implement coordinated programs, many times still people are treated inappropriately in State hospitals, or even more unfortunately in some cases they are on the streets.

In my city of Philadelphia, we estimate 10,000 homeless people and of that 10,000 about 3,000 are severely mentally ill. It is a daily event in terms of seeing people suffering on the streets. This is a Federal responsibility, in terms of developing programs and coordinating and doing as the community support program has done, which is to reach out and develop within the States the responsibility and programs and helping those States coordinate.

A little money has gone a long way in that program. We need to expand that program. Any efforts that you can make in that area we hope to support. One of the things that we are very concerned about in the consumer movement is us taking a role and us having a role in making a difference.

One of the things that I am happy for is to have this opportunity today to let you know about our movement. We are a relatively new movement. The family movement has been developing and is a strong movement, and we support the organizing of the families in the National Alliance for the Mentally Ill.

We, in the consumer movement, and our self-help groups are also coming together and the National Mental Health Consumers' Association is an opportunity, with our local groups, such as Channel One in New Mexico, and such as Catalyst for Change in Connecticut, for consumers to come together.

When you opened this conference, these citizens who can speak out on these issues and not be ashamed of the fact that they too have suffered from mental illness and speak to their fellow citizens and get those citizens to understand that this is something that has an impact for all of us. I again thank you for the opportunity to speak.

PREPARED STATEMENT

Senator WEICKER. Thank you very much. We will place your statement in the record at this point and then Senator Domenici has some questions to ask of you.

[The statement follows:]

STATEMENT OF JOSEPH A. ROGERS

I am grateful for the opportunity to appear before you this morning to discuss the needs of people with mental illness in this country. My name is Joseph A. Rogers, and I am Chairperson of the National Mental Health Consumers' Association, Associate Director for Special Projects of the Mental Health Association of Southeastern Pennsylvania, and the founder of Project SHARE, a consumer-run self-help organizing project in Philadelphia. I appreciate this opportunity to bring to your attention what is a massive problem.

There are huge numbers of individuals in this country who suffer greatly from mental illness--particularly the major mental illnesses such as schizophrenia and manic-depressive disorders.

Mental illness is something that I know a lot about personally. I have been diagnosed as a paranoid schizophrenic. From the age of 19 until I was 26, I was in and out of various hospitals, lived in a halfway house for people with mental illness, struggled trying to maintain myself in the community, struggled with such issues as employment and housing, and spent periods of time homeless in the streets of New York City and Atlanta, Georgia.

Over the years, I have found that there is very little understanding in the community of the problem of mental illness, and a lot of fear. There's a great deal of stigma, a negative attitude on the part of the public and, unfortunately, in many communities on the part of public officials. There's a feeling that we must sweep this illness under the rug; we must lock the people away; we must not deal with it.

I think that has had an impact on us in many ways. I have felt the stigma of mental illness personally: Watching television, I see one show after another characterize us as either extremely violent or as buffoons. This hurts me and--I know from my work as Chairperson of the National Mental Health Consumers' Association--it hurts millions of people who have suffered from mental illness. These people are human beings just like everyone else. These people, like myself, need a break, need a chance to work, need a chance to be part of the community. But because of the stigma, the negative portrayal in the media, the attitude on the part of the public and public officials that we are "different" and should be shunned, we suffer. In fact, there is a growing public attitude that the best thing for us would be reinstitutionalization--that society would be better off if we were locked away out of sight.

Stigma affects not only our ability to live normal lives in the community; it even affects our ability to recover from the illness and to get the supports we need. We are portrayed negatively in the media and are stigmatized by officials in government-sponsored programs, and we are discriminated against. For example, In Philadelphia last year, the Public Housing Authority, a federally funded project, wanted to institute regulations that would require people with a history of mental illness to undergo special screenings before they could qualify for public housing. Luckily, we were able to focus the attention of the media on this problem and to eventually get the attention of the federal authorities, and the Public Housing Authority was forced to withdraw these discriminatory regulations. When programs that have been set up for poor people, for people that have problems, exclude us because of the stigma and the negative image, it's crucial that we support programs on the federal level, such as the National Institute of Mental Health Community Support Program, and encourage those programs to develop coordinated national campaigns to fight stigma and discrimination against people with mental illness.

Stigma and the negative attitudes toward people with serious mental illness also affect such areas as research. We seem to always be on the bottom of the pile when it comes to research dollars.

When I first came out of the hospital, I was given a promise. I was told that there were medications, that there were programs, that there were ways that I could deal with my problem. This promise has not been fulfilled. Though the medications were helpful, there are serious side effects. These side effects have not been researched. It seems that all of the research in terms of medication for the mentally ill ended in 1957 or 1958. There hasn't been much of an effort to move beyond the existing technology, which, although helpful, is far from perfect. Massive numbers of people don't respond to any existing medication. Or, if they do respond to the medication, it's on a minimal basis, and they still need many other supports. Or they develop serious side effects from the medication which cannot be controlled. Many psychotropic medications carry the risk that the user will develop tardive dyskinesia--uncontrollable and disfiguring facial and body movements. Tardive dyskinesia is an irreversible condition.

When I first started taking psychotropic drugs in 1972, I asked the psychiatrist, "How does this work? How is this helping me? How can I deal with the side effects when I get them (and I did get side effects)"? Fourteen years later, these questions have still not been answered. There still seems to be a woeful lack of understanding. The need for research in this crucial area is probably the Number 1 need in mental health today, and

I think it's criminal for us to use valuable research money, as Dr. Torrey has documented in his testimony, in areas that don't address this most devastating problem. It is simply not cost-effective.

If we are willing to pay the bills, there is much that can be done in this area. I've seen some of the preliminary research that the National Institute of Mental Health has begun to institute in this area, and I have a lot of hope. There's been research to develop the best ways to use the existing medication, so that you don't overmedicate people and so that you can train individuals to medicate themselves on an as-needed basis so that they're not on massive doses over long periods of time. These things work, but more research is needed and help is needed to implement them in the field.

There are good programs that exist right now, but they need more support. The National Institute of Mental Health Community Support Program is extremely under-funded and needs massive infusions of cash to carry out its work. Even with the limited funding it now has, it has done a good job of beginning to get the state governments involved in coordinating vitally needed services. Not only do we need to research the biological causes of mental illness, but we need to begin to implement what we already know in terms of rehabilitating people who have recovered or are recovering from and struggling with long-term mental illness. There are psychosocial programs that do work. There are rehabilitation programs that do get people back to work. But these programs do not seem to get the funding, they do not seem to get the support. In spite of this, programs like the National Institute of Mental Health Community Support Program have done an excellent job in such states as Ohio, my state of Pennsylvania, and many other states, of using a relatively small amount of federal dollars to help coordinate and implement new technology and new services in the states. This program vitally needs your continued support. We thank the Committee, and particularly the Chairperson, for supporting the Community Support Program, and urge that this support be expanded.

We plan to do our part. The National Mental Health Consumers' Association, which grew out of the grassroots self-help movement among mental health consumers, was founded in 1985 at a conference in Baltimore to organize mental health consumers--to bring us out of the closet. At that first meeting, over 400 consumers elected representatives from around the country to form the national organization. At our second annual national conference, in August 1986, we expanded the number of representatives.

Over the last year and a half, the National Mental Health Consumers'

Association, of which I am Chairperson, has earned a national reputation as an advocacy organization. We have taken a stand nationally to fight stigma, protect patients' rights and empower mental health consumers. We have educated people nationwide about the Protection and Advocacy for Mentally Ill Individuals Act of 1986. We have compiled a national directory of consumer advocates and distributed it to the 50 state P&A agencies. We created a program called CONTACT, with the National Mental Health Association, to link the P&A system with the skills and talents of consumer and other advocates. We sponsored three amici briefs before the U.S. Supreme Court to protect patients' rights. We have educated people and testified before the U.S. Senate on bills affecting us. We have joined in a national drive to register disabled voters. We have fought the media's attempt to link mental illness with violence, through TV and radio appearances, newspaper interviews, and press releases. We have sponsored a major panel discussion on stigma and discrimination.

The National Mental Health Consumers' Association has also established a national clearinghouse to facilitate the exchange of technical assistance between self-help groups and promote their development and networking by means of financial grants and information, and through referral to a list of 100 consumer consultants. We have helped hundreds of consumers with their local group efforts in such areas as fund-raising, public relations and leadership development. We have kept potential funding sources informed about national and local efforts. And we have begun the vital work of building coalitions with other advocacy groups, urging them to recognize mental health consumers as a national force.

The projects that we have developed in the National Mental Health Consumers' Association to strongly support the development of the Community Support Programs, to develop a program of educating the public around stigma, and to attack stigma by developing our own self-help organizations--these groups and programs are run by present and former mental health consumers. These programs are largely funded through Community Support Program funding and are also seeking funding from the Protection and Advocacy program, in which the Chairperson has played such a crucial role.

These programs are self-help groups which are run by people who have been in mental hospitals themselves, people who have "been there." We feel one of the best ways to attack the negative attitude of the public is to show that we are not only capable of overcoming our illness and establishing ourselves in the community with supports, but we are able to create some of those supports ourselves through self-help groups. I strongly urge the

Chairperson and the Committee to investigate the possibilities of continuing and developing supports for the self-help movement, as part of the continuum provided through such programs as the Community Support Program and the Protection and Advocacy Program. I also want to applaud the Chairperson and others who supported the Protection and Advocacy legislation for recognizing the mental health consumer movement by requiring that 50 percent of the state advisory committees to the Protection and Advocacy Program consist of consumers and/or their family members. This was a very progressive step. We need to expand those kinds of efforts to include the mentally ill and the families of the mentally ill in the development of programs. Who can understand our needs better than we can ourselves? Who can better judge whether a program is beneficial than we or our families?

I applaud this hearing. But I hope that we do more than just hold hearings; I hope we begin an agenda. I think we have a chance to turn negative influences to positive directions. Even though there seems to be a negative attitude in the media and the public about the mentally ill, at least attention is being paid to the problem. If we have leadership, if we have commitment, we can move forward. Senator Weicker has already demonstrated that kind of commitment and leadership. We in the National Mental Health Consumers' Association and the consumer self-help movement are proud to join in the struggle to bring about these much-needed changes.

Thank you very much.

Senator WEICKER. Senator Domenici?

Senator DOMENICI. I just want to thank him. I think he is right on.

Senator WEICKER. I would like to reemphasize one point that he made. That is the Federal role. I find across the spectrum there are a lot of people that say that we don't need the Federal Government.

Let me say this right now, when I was in the State legislature in Connecticut in 1963, the State of Connecticut, under the leadership of Democratic Gov. John Dempsey, had the finest program in caring for the mentally retarded. That was Southbury Training School.

It was better than anything available in any other State or indeed any effort of the Federal Government. We were proud of it, indeed. Then when I moved to Washington in 1968, I would have Congressmen come to me to ask how their constituents could place their children, loved ones, in either Southbury or Cromwell children's homes.

In the intervening time we passed Public Law 94–142 and various other statutes vis-a-vis the care of the retarded. The year is now 1986, and in 1985, the State of Connecticut was being sued by the Federal Government for the inadequate care of the mentally retarded at Southbury.

The point that I am trying to make is that, quite frankly, the political clout either at a local or a State level isn't there. The votes aren't there for these people. When the money gets divvied up and the resources and the attention gets divvied up, there is no political connection and these things tend to slide into the forgotten corner.

If it wasn't for the Federal law bracing up the State of Connecticut, believe me, these people would not have the care that is owed them as citizens of this Nation. Anybody that says we can handle it in a block grant way, let the States handle it, States' rights, et cetera, is nuts.

The unique role of the Federal Government is to come to the aid of some minority that is going to be forgotten, whatever the reason is—physical, mental, color of skin, economic—I don't care. That is the special role, it seems to me, that was always envisioned for the Federal Government.

I know you emphasized this and I think it has to be emphasized.

Mr. ROGERS. If I could just say that, in terms of, both the protection and advocacy and the community support programs have done just that. They have done it in a way and they are doing it in a way that involves the people in the State.

One of the things that I want to point out is that the percentage of having consumers on the board of the protection and advocacy allows us, local consumers, for the first time to come together on a statewide basis in Pennsylvania, to coordinate services, protection and services, so we really want to thank you for that addition to the legislation. It does that, it allows for us now to begin to address a problem that, for whatever reasons, the State was just not moving.

In Pennsylvania, we have never had a really coordinated effort to protect the rights of the mentally ill, and in the community support programs many times you will have State agencies that wouldn't talk to each other. Having that one additional person, at very little cost, there, the community support director, to help them coordinate and then also to bring together on a national basis the knowledge and dissemination of the technology. We can put all the money we want into research, but if the Federal Government doesn't play a program role in helping that knowledge and information get out to the States, it is useless. It is a waste of money.

Senator WEICKER. I thank you very much for your testimony. It was wonderful to have you here.

STATEMENT OF DONALD RICHARDSON, PRESIDENT, NATIONAL ALLIANCE FOR THE MENTALLY ILL

Senator WEICKER. Next, we have Mr. Don Richardson, president, National Alliance for the Mentally Ill from Los Angeles. It is nice to have you here.

Mr. RICHARDSON. Thank you, Senator Weicker, and thank you so very much for making this possible.

Senator Domenici, thank you for being here too.

I think it is appropriate for me to follow Joe, because the type of illness that we are talking about is truly a family affair. Everybody in the family is afflicted by this illness that has reached so many millions in our country.

As a symbol of why we are here, the families who are suffering with this illness are so very hopeful that something will come out of this. Those who are struggling day by day, holding on by their very fingernails, hoping that something is going to break through that will bring some kind of tranquility, some kind of hope.

If having an opportunity to see our consumers come forth, those who have gone through the hell of schizophrenia and are beginning to show you that it is possible for something to happen that is positive. That is the kind of hope that we are seeking as families.

Seventeen years ago, my oldest son graduated from the University of California, Berkeley Campus. A year later he was in a psychiatric hospital, his diagnosis, schizophrenia. Today, he is in a psychiatric hospital, the third time in the last 2 years.

Thirteen years ago my youngest son became a part of the mental health system, he was diagnosed schizophrenic. Now after 38 hospitalizations, he is in jail serving a 6-year term as a common criminal.

The list of admissions to this place and that place has become four single-spaced typewritten pages. Some of the entries say missing, some say discharged to the streets, some say dangerous to self, dangerous to others, and all those words which mean that my sons are sick. They have a disease that must be found the cause of and something must be done.

I think that anyone looking at this list of four single-spaced pages must realize that something is wrong, something unacceptably wrong. I know that when I look at the list I get very angry, and there are a lot of angry people in America who are trying to somehow survive this illness.

We parents find a lot of nice people who want to help our mentally ill people. We find that the police are nice, and they try very hard, but their hands are tied by laws and redtape and lack of money. We talk with conservators, we talk with the chief of psychiatry, the therapists, the nurse, and they are nice people, and they wish things were different, but they don't have enough money, enough space, enough staff. They literally wallow in rules and regulations.

We parents talk with everyone. Everyone would like to do better but they feel that they must follow the rules, the department orders, the law. I am just wondering, if we are not dealing here with perhaps the Nuremberg principle where everyone follows the rules and then nobody is guilty, or perhaps it is everybody follows the rules and everybody is guilty.

Whether you are a part of the system or trying to do battle with it, the difficulty is that everything is piecemeal. I have heard that as a theme throughout these testimonies. In reality, we really don't have a system. We have a framework that is comprised of pieces put together by a bunch of nice people. The administration of the State and county mental health department is piecemeal, services are piecemeal, and change depends upon funding of isolated bits and pieces, which in turn becomes a piecemeal loaf.

I say, and again, thank you so very much for making this possible, that it is time for a change. It is time that the mental health system becomes a reality in this Nation. I think the emphasis on the disease, the bringing out of looking at the existing nonsystem, which many of us agree that that is a better term, and then we would begin to see what is the framework around which we can really do something, that we know we have the capability of doing.

The most common question that is asked those of us in a leadership role of our national family movement is, when is something going to happen? It took my wife and I a long time to accept the fact that our sons were mentally ill. It took us a long time to become visible members of the Alliance for the Mentally Ill.

We told no one in our professional contacts about our sons. We didn't even tell our closest friends about this terrible disease, because of the stigma that is associated with mental illness. It is a painful experience to come out of the closet but as you can see I am out of the closet.

There are literally thousands and millions of people who are beginning to take that first painful step out of the closet and say we know we didn't cause this disease, it is about time that we, as citizens, begin to say we are with you. We are with you Senator, and I am whereever something has a possibility of developing to give us answers.

With the stigma comes so much work, and I am pleased and proud of what NAMI, the National Alliance for the Mentally Ill, has been able to do when we become visible as a unit. To give just a very brief summary of a large number of activities, we received 1,500 letters after a very, very brief appearance on "Good Morning America," 5,000 letters poured into our Arlington office after an article about NIMH appeared in Parade magazine. A rerun of the "Phil Donohue" show that featured Dr. Torrey brought in, I happened to be in the office in the 5-day period, and I really told my staff that they didn't have to impress me quite that way, because we received over 3,000 phone calls in those 5 days at that office. We received over 5,000 letters and this was a second, a rerun, the first time this program where Dr. Torrey was so specific and was so dynamic in saying you out there public, we need you, let's get behind this and do something about it. That first time our office received over 7,000 telephone calls and letters.

I could go on and on, but it tells that there is a need and the fact that our folks are no longer feeling that they are alone, which is that terrible loneliness when you say, golly, I must have done something, and you begin to internalize and get that terrible stigma.

This brings us to the topic of supportive living and services for the mentally ill people in the community. Because of the cyclic nature of serious mental illness, it is essential that each community have a continuum of services that will provide support for the state of the illness at any one time.

Most mentally ill persons are able to function in the community, and I think that is so important for our public to understand. They can function in the community if they have decent housing opportunities for developing living skills, have vocational opportunities, and easy access to professional consultation and medication monitoring.

It is essential to have a case manager, or a team, or someone who can link the persons up with existing services, but are often underutilized because the nature of the illness does not allow them to come forth, in many cases, and use those services that are already there.

A common question asked of NAMI is, how do the programs in the highly rated States achieve better services and apparently are not needing to spend a lot of money.

Again, I want to publicly thank Dr. Torrey, Trish Van Devere Scott, who have taken such a magnificent leadership in books and in publications.

There is in a publication called "Care of the Seriously Mentally Ill, a Rating of State Programs," and it is coauthored by Dr. Torrey. In that it points out that money is not the answer. It is how you use the money. It also points out that if you give a high priority to this illness, you can do something about it.

I think it is about time that our Nation comes forth and realizes that. I think as a summary statement, I would like to emphasize two or three items in my closing.

I think it is overwhelming when we realize that the numbers of people and families who are seeking this help. I think each national exposure, as was so evident in the statistics, again, emphasizes that interest, that need, and that camaraderie, that can be developed.

The role of stigma looms big whenever we try to advocate for comprehensive community programs. That comprehensive community program must include social opportunities, vocational opportunities, and available insurance that has a comparable emphasis on this catastrophic illness along with other major illnesses.

Because of the major mental illness, we feel that this is a major thrust that perhaps the Federal Government along with the State governments can assist in bringing to a higher point of visibility and need.

Research, of course, I would have started and perhaps given my full time to the research, but it has been done so eloquently and so thoroughly, that I only want to say, sock it to them. We have got to do more in that line. We must look at how the current research is being done.

In closing I want to emphasize the hope, the courage, and the vision, that are such vital parts of the Alliance for the Mentally Ill movement. We family members are growing in number, in knowledge, and in skill as to making the system help us rather than frustrate us.

More importantly, however, is that as we mature as an organization we are learning the value of the, I suppose, the Thanksgiving season, which is about upon us. What I mean by that is that we are learning as families that the art of thanksgiving is also the art of thanks living. It is gratitude in action. It is learning that as we receive the assistance and the inspiration from those who joined our efforts and our movement, we are gaining a huge reservoir of challenges, inspirations, strength, understanding, and encouragement.

NAMI appreciates this opportunity to place on record our goals, our objectives, and our priorities. Even though we are a young organization, we are aging quickly in stature and credibility. We are going to be around for a long time and I think we should recognize that. We are not going to go away.

We have as an inspiration the story of a man who planted a tree when he was 95 years old. When he finished planting that tree, he commented that he could hardly wait until he could pick the fruits of his labor.

PREPARED STATEMENT

Senator WEICKER. Thank you. We will place your statement in its entirety in the record at this point.

[The statement follows:]

STATEMENT OF DONALD RICHARDSON

I want to thank Senator Weicker and this subcommittee for the opportunity to highlight the family perspective relating to stigma associated with serious mental illness, to emphasize research as a top priority and to advocate for a continuance of care that serves our family members as they try to survive in the community.

Seventeen years ago my oldest son was hospitalized. His diagnosis - schizophrenia. Thirteen years ago our youngest son was hospitalized. His diagnosis - schizophrenia.

It took my wife and me a long time to accept the fact that our sons were mentally ill. It took as a long time to become visible members of the Alliance for the Mentally Ill. We told no one in our professional contacts about our sons, we didn't even tell our closest friends because of the terrible stigma associated with mental illness. It is a painful experience to come out of the closet. But, as you can see, we are very much a part of the most dynamic and visible movement of the century. Hundreds of thousands of families across the nation are challenging the allegation that families cause schizophrenia. Thousands are speaking publicly that they have a mentally ill relative or that they themselves are recovering from mental illness. These folks have taken their first frightening step out of the closet and many are joining the Alliance for the Mentally Ill (AMI) every day.

Dr. John Talbott, the former President of the American Psychiatric Association, has said on many occasions that when families speak out about mental illness and join AMI they have taken the best antidote known for reducing stigma. As our movement grows we are finding as did the families with retarded children and other handicapped Americans that our effectiveness in reducing the stigma and educating the American public about the illness is bringing about positive results. Our media watch committees throughout the nation are quick to bring to the attention of producers and editors unacceptable presentations of mentally ill persons. Advertising and manufacturing of consumer products that stigmatize mental illness are countered through educating the designers, the owners, the Boards of Directors about the illness and bringing to their attention the hurt their efforts are causing these vulnerable humans in our population.

Two years ago there was little visibility of mental illness. Today that has changed. NAMI members are telling the media the truth about the illness in their family. They are reminding all who will listen that three or four persons out of every hundred will suffer severe and long term mental illness and those individuals could be in any family since this disease knows no restrictions of race, color or creed.

Because of unbelievable amounts of human energy being expended throughout our 50 states, AMI affiliates have been able to obtain outlets for bringing mental illness into the open. We are seeing the beginnings of more sensitive and concerned interest on the part of the American public. The best way to demonstrate the impact of this energetic movement is to summarize what happens when NAMI becomes visible:

* 1,500 letters reached our national office after NAMI was featured on "Good Morning America.:

* 5,000 letters poured into our Arlington Office after an article about NAMI appeared in Parade Magazine.

* 1,481 letters clogged our mail room after a Reader's Digest article about NAMI appeared this summer.

* A rerun of the "Phil Donahue Show" where our NAMI's phone number was given resulted in over 3,000 telephone calls in five days. We received over 5,000 telephone calls and over 1,000 letters since the August showing. Last year, the first viewing of this program resulted in over 7,000 telephone calls and letters.

* Television specials on mental illness such as "Nobody's Child" have brought positive understanding of this terrible illness.

* CBS will view on December 14, 1986, a special on siblings who have mentally ill brothers or sisters. "Promise" stars James Garner as the brother who promised his mother that he would take care of his mentally ill brother after the parents' death.

* In September, Ann Landers addressed her column to siblings of those with mental illness. Over 4,000 letters to NAMI resulted from this column.

The role of stigma looms big when we advocate for a comprehensive community-based program for our mentally ill relatives. It too often is a battle with those in the community who often agree that the mentally ill should live in the community but not in their community. However, NAMI is finding that when neighborhoods are properly educated about mental illness, they are accepted and usually there is a unified reaction that reflects support for their right to be there. The very experience of placing our people in the neighborhood has helped to combat stigma and to replace ignorance and fear with understanding and acceptance.

This brings us to the topic of supportive living and services for mentally ill persons in the community. Because of the cyclic nature of serious mental illness it is essential for each community to have a continuum of services that will provide support for the stage of the illness at any time. Most mentally ill persons are able to function in the community if they have decent housing, opportunities for developing living skills, vocational training and easy access to professional consultation and medication monitoring. It is essential to have a case manager or team to link the individuals to governmental services that exist but often overlooked or underutilized by this population. Perhaps 80% of NAMI's efforts is devoted to developing a comprehensive residential and rehabilitation support program in the communities of America. Since decisions regarding community facilities and services are controlled by state laws and local ordinance, NAMI encourages and assists where possible the advocacy at the state level. A common question asked of NAMI is how do the programs in highly rated states achieve better services without spending more money. Clues came from the recently released publication, "Care of the Seriously Mentally Ill: A Rating of State Programs," co-authored by E. Fuller Torrey and Sidney M. Wolfe. Colorado designates the seriously mentally ill as its first priority for the use of state mental health dollars. Rhode Island provides decent community housing for the mentally ill through special local taxation. Wisconsin fixes fiscal responsibility at the county level and assures that the dollar follows the patient. Dr. Torrey emphasizes that the best state programs for the mentally ill require effective state mental health leadership, supportive governors and legislatures, and strong Alliance for the Mentally Ill affiliates. The third and most unifying topic of importance is the families' support for research into the causes, cure and prevention of this terrible disease.

It is accepted by the most prominent researchers that serious mental illnesses such as schizophrenia and depression are brain diseases. They are recognized as serious biological entities along with such illnesses as diabetes, multiple sclerosis, and cancer. Schizophrenia, the most debilitating mental illness, exhibits symptoms such as impairment in thinking, delusions, hallucinations, changes in emotions, and changes in behavior. And, like cancer, it probably has more than one cause. The term depression or affective disorders refer to changes in mood that occur during an episode of illness marked by extreme sadness or excitement, or both.

Schizophrenia is emerging as the most complicated illness and therefore the most serious health problem facing the nation. But there are important and encouraging signs of hope beginning to surface.

Interviews and an extensive review of medical journals and scientific papers reveal that the nation is moving toward a new era in both understanding and treating schizophrenia. It is gratifying to witness the efforts of the mass media to help educate the public about mental illness. The New York Times, for example, published this year a state-of-the-art series on schizophrenia that brought the problem and a review of progress to the attention of a great many people. There has been encouraging discussions of issues pertaining to mental illness research that have been appearing regularly in journals such as Science.

It is important to realize that two to three million Americans either have or will develop schizophrenia at some point in their lives. It is estimated that an additional four to six million citizens suffer serious depressions that lead to the enormous cost in health and productivity of these individuals. The good news is that new studies have shown that the outlook for serious mental illness is not as dismal as it was just a few years ago.

Roughly half of all schizophrenics eventually get better according to five recent studies.

Positive changes in attitudes by professionals toward families have encouraged collaborative efforts that are proving to be productive in research activities. The old notion that families were to blame for causing the disease has given way to the notion that biological factors play a major causative role. The National Alliance for the Mentally Ill, a family self-help organization, in less than a decade has performed an extraordinary job in relieving the sense of isolation that can be so much a part of the disease, and in providing the advocacy so desperately needed. It is this growing activism on behalf of the mentally ill that formed the nuclei around which the National Alliance for Research on Schizophrenia and Depression (NARSAD) was developed. In July of this year, 1986, four existing mental health groups collaborated to assure that NARSAD's mission is accomplished:

> To raise and distribute funds for scientific research into the causes, cures, and prevention of chronic and severe mental illnesses, primarily schizophrenia and depression. This mission is to be accomplished by increasing public awareness and knowledge concerning these diseases."

In closing I want to emphasize the hope, the courage, the vision that are such vital parts of the AMI movement. We family members are growing in number, in knowledge, in skill as to making the system help us rather than frustrate us. More importantly, however, is that as we mature as an organization we are learning the value of the Thanksgiving season that is upon us. We are learning that the art of thanksgiving is thanksliving. It is gratitude in action. It is learning that as we receive assistance and inspiration from those who join our movement we are obtaining a reservoir of challenges, inspiration, strength, understanding, and encouragement. NAMI appreciates this opportunity to place on record our goals and objectives. Even though we are a young organization we are aging quickly in stature and credibility. We are going to be around for a long time. We have as our inspiration the story of a man who planted a tree when he was 95 years old and commented that he could hardly wait until he could pick the fruits of his labor.

STATEMENT OF SENATOR D'AMATO

Senator D'AMATO. That is a very optimistic note.

First, I commend Chairman Weicker for his commitment to understanding and stopping schizophrenia. It is my hope that increased recognition of and financial commitment to this disease will help reduce its high incidence in this country.

Schizophrenia afflicts 1.6 million Americans and accounts for 40 percent of all long-term care, institutionalized days in the country. Every individual has a 1 out of 100 chance of developing the disease.

The origins of the disease are not fully known. Research indicates that there may be a biological basis for schizophrenia.

Schizophrenia has complex symptoms. The disease commences with psychological turmoil and progresses to severe distortions in perception, speech, and thoughts. Some examples of these distortions are having paranoid delusions, believing that outside forces are controlling thoughts, hallucinating, and experiencing blunted or inappropriate emotions.

Treatment of schizophrenia generally combines therapies. Antipsychotic medications, psychotherapy, family therapy, and additional therapeutic methods are used to combat the disease. Much of the progress in treating the disease results from medications. Fifty-five percent of schizophrenic victims who do not take medications will suffer a relapse within 2 years of being discharged from a psychiatric facility. That compares to a relapse rate of 20 percent for victims who do take medication.

Schizophrenia can be effectively treated. One study indicates that as a result of treatment 25 percent of a group of 2,000 patients fully recovered, 50 percent recovered partially, and 25 percent required lifelong care. These statistics clearly indicate the hopefulness of combating schizophrenia.

Funding for schizophrenia research has drastically increased over the last few years. In fiscal year 1984, $16.8 million was appropriated for research efforts to combat this disease. This figure increased to $26.7 million for the fiscal year 1987 appropriations cycle. I fully supported this increase in funding, and I commend Senator Weicker for his evident commitment to overcoming this disease.

Again, I thank Senator Weicker for drawing attention to this disease and for recognizing the feasibility and necessity of tackling schizophrenia through increased research efforts.

Senator DOMENICI. I thank you very much, Senator D'Amato.

Mr. Richardson, let me just thank you for your testimony. Not only have you factually described the deplorable situation that we have out there, but, I think, you have in a very real way indicated to us, those of us who want to do something to rid our Nation of this terrible problem, first curing it if we ever can, but I mean treating it in the mean time, you have pointed out to us that those who suffer by way of family relationships, that you understand that this is a difficult problem.

One of the great side effects of being associated with NAMI is that while you look out there at 1,500 national conventioneers and they are all suffering and worried, they really are very reasonable, marvelous people, maybe it is because we have had so many hard knocks that they have a little more hope.

I believe that we have to listen up here. I think this issue is complicated, but also in some respects the problem is simple in terms of being helpful in the short term. You all are telling us how to do that. We just have to. We just can't say we can't, we just have to say we have got to do this.

I urge that, as I did before and I want to do it right here publicly, I believe you ought to come up with an agenda as you have and it will always be reasonable with people like you and others putting it together. I just don't think you can take no for an answer up here. I don't believe you can let anybody say we don't have the resources for this, if it is something that we really need as part of getting out of this problem.

I just think you have to insist that Congress listen, that legislators listen, and Governors listen. I tell you I believe they will. I honestly believe that we are on the threshold of some real breakthroughs, both in terms of research, assets, talent, but also we are on the threshold of getting the health care people of this Nation to help us coordinate these efforts.

It is absolutely a disaster out there in some of our States. I mean, one old, old mental hospital becomes the focal point because it has been there and because legislators have been funding it. To find the next step is just very, very difficult out there in our cities and States. To make those ties that have to be made to get the people related to help with this problem.

The complexity causes people just to shun it and say let's do more of the same. So I just encourage you in your capacity and all of the members and other groups that have the same goals to be persistent. Don't worry about being too demanding, or too pushy, get those people involved legislatively. As I told you before, make them tell those people that get elected that they have got to solve this problem. Put a little of the fever and furor into helping candidates and helping politicians and then don't take any no's from them.

I really believe we can get it done, so I want to compliment you for being so forthright with us. It is very difficult for you to sit here and tell us about your family and your two sons, but I hope you understand that, while many of us have great, great concerns, we have nothing but pride about people like you. Thank you very much.

Senator D'AMATO. Do you have any other questions?

Senator DOMENICI. Maybe I would ask for the record, how fast is NAMI growing so that the politicians who might read it will understand?

Mr. RICHARDSON. Thank you for asking that, because I was going to interject it somewhere along the line, because it is a phenomenal picture. The comment that I have verified again, that had been made so many times, is that we have a new affiliate join the national organization currently every 36 hours.

We currently have 652 affiliates that make up the membership of the national alliance. I thought that because that one I just shared with you had been used quite a bit, I would come up with another little statistic because it is also very accurate. Checking with our office a couple of days ago, I was told that there is a family, somewhere in America, joining a NAMI group, somewhere in America, every 6 minutes of the working day.

When I say when I last checked how many were members, it is truly a challenge to just keep up with that growth. It has brought many problems.

Another little thing before I close completely, when we were talking about this growth our accountant informed me that if we maintained the growth of the current NAMI movement, we will exhaust our current computer capabilities in 9 months. [Laughter.]

Senator D'AMATO. Well, that is an impressive record.

Senator DOMENICI. We hope you do that, to get the computer people thinking about the next computer.

Mr. RICHARDSON. I have to admit it is a problem I love.

Senator DOMENICI. Good.

Senator D'AMATO. A poll cited by Dr. Torrey from Science magazine, found that 55 percent of the public does not believe mental illness exists and only 1 percent think that mental illness is a serious health problem.

That is a powerful tie to ignorance and it is clear from your testimony that the National Alliance for the Mentally Ill, NAMI, is actively involved in stemming this tide of ignorance. I believe that before you are going to have the kind of success necessary to get the kind of funding to undertake a meaningful battle, we are going to have to help stem that tide and turn it around and educate people.

Notwithstanding my colleague's feeling of optimism, I would have to suggest that, if history is any lesson, that this body and the Congress doesn't move until the public becomes aroused. It must be the public that really brings pressure.

So, the question that Senator Weicker was very anxious for you to address, so that we can get it out in the record, is, what do you believe the Federal Government ought to be doing to educate the public and how can we assist you in stemming this tide of ignorance?

Mr. RICHARDSON. I think the very fact that you are doing what you are doing today is an excellent approach to educate the public. We also are hopeful, and there have been, certainly, supportive actions of the Federal Government to continue to do such things. They are small, perhaps, in action, but they are very meaningful.

The approval of Congress of the Mental Illness Awareness Week. We celebrated the second. We recognized the second year of Mental Illness Awareness Week. That is a very key part of bringing to America this issue. For your information, during the Mental Illness Awareness Week of October 6 to 12 of this year we had the Goodyear blimp floating around giving the NAMI message. That is an issue that very few are aware of, but it was the awareness of the recognition at the Federal level.

I was told that the cartoonist, who is responsible for Dr. Rex Morgan, M.D., is going to mention NAMI as the most reliable and the most valuable resource for families who are seeking help in serious mental illness. That is supposed to come out in December, so I have suddenly recognized that there is a cartoon strip called Dr. Morgan.

I think the prestige of Congress indicating that in spite of the budget deficits, in spite of the horrendous problems that this Nation has fiscally, perhaps, as it was mentioned earlier, perhaps the priorities could be much different, and recognizing that dollars do make a difference, they do make an impact, and if our research units, our institutes, can get a budget that is, even just somewhat comparable to the dollars of our other major illnesses, $14 is all that is spent on research by the Federal Government for research of schizophrenia. You compare that with $10,000 for AIDS, $300 for cancer, and we can go on and on.

It just doesn't make sense to have the most serious and the most debilitating illness in our country to have such a low priority. This can be a very, very important goal of Congress.

Senator D'AMATO. Let me thank you for your time, and hope that your computer runs out before that 9-month estimate.

Mr. RICHARDSON. Thank you very, very much.

STATEMENT OF HERBERT PARDES, M.D., CHAIRMAN, DEPARTMENT OF PSYCHIATRY, COLUMBIA UNIVERSITY, REPRESENTING THE AMERICAN PSYCHIATRIC ASSOCIATION

Senator D'AMATO. Dr. Herbert Pardes. Doctor, it is good to see you again.

The doctor has been a frequent visitor to hearings held by this subcommittee both in his former capacity as the Director of the National Institute of Mental Health and his current capacity as chairman of the Department of Psychiatry at Columbia University. He is testifying on behalf of the mental health research community, he is here today representing the American Psychiatric Association. Welcome back, doctor.

Dr. PARDES. Senator, it is a delight to be here and I think it a privilege to present to you, as our leader in New York, and a leader of whom we are very proud.

I am also pleased to present to this committee, in that it has been continually supportive of many of the concerns that we have about mental illness and the necessary programs to address it.

I do appear before you as vice president of the American Psychiatric Association, the head of its council on research and I will submit the formal statement for the record. I would just like to make a few points of emphasis.

I think clearly that this is a time to build a team. A team which will make a major attack on this illness, something that has waited for some time. And your point regarding the number of American people who do not take this issue seriously and tend to avoid it, is one of the essential points that has compromised our ability to get this on the public agenda.

We are appealing for support in elevating mental illness and schizophrenia particularly for top priority status as recently recommended by the Institute of Medicine of the National Academy of Sciences. The fact sheet that we will submit will go over some of the details.

I will suffice to say that this is an horrendous disorder, probably as unattended as any disorder there is, and affecting an enormous number of people, and afflicting the patients themselves, their families, their friends. Its cost is devastating and I think you have heard eloquent statements from Ms. Van Devere, Dr. Torrey, Mr. Richardson, to that effect.

I am particularly grateful to Ms. Van Devere for helping to get this hearing going. Schizophrenia is a disabling constellation of mental disorders, most likely. It has been a concern of the NIMH since its inception. It is not likely a single illness but rather a group of illnesses and it has become clear that brain factors are much more central than have been thought before.

One of the concerns we have is that there be a broad attack of many scientific disciplines, no premature closure as to what causes these various diseases, but an attempt to get the best of the sciences in on trying to solve it. I might add that one of the critical issues in many psychiatric disorders is that they tend to involve both biological and behavioral factors. If you think of teenage suicide, if you think of manic depressive disease, if you think of schizophrenia, they involve really a constellation and one has to look at all of it.

However, it is clear that we think that research in the area of neuroscience and brain disease is critical in this regard. Schizophrenia has been a difficult field to attack, difficult in some degree by virtue of the absence of substantial citizen support, difficult by virtue that the illness is so varied and that the illness may differ from patient to patient. Some of the treatments produce side effects, and as a result complicate the issue even further.

In addition, there has been an almost volatile instability of funding for support for this research endeavor and I hope that what we are signaling here is some consistency in terms of that support. There have been many before the citizen movement really got going, who are out there fighting often singlehandedly to try to develop sufficient support for this.

At NIMH there has been a rather underfunded battle for new knowledge of schizophrenia for some time. The NIMH expertise ranges from brain to behavior, from research lab to community, and has put it in the uniquely qualified position to address the multifaceted dimension of this illness.

The researcher, both basic and clinical. I might add I think it has to be understood that NIMH has a very strong basic brain research program, as a matter of fact, during my tenure at NIMH I instituted the first neuroscience branch within the NIMH to get greater attention to brain research as it impinges on these clinical disorders.

The NIMH's research has been responsible for some of the information that we do have, information that produced psychopharmacological drugs which do help, information which showed that attention had to simultaneously be given to a variety of social and psychosocial issues in the rehabilitation and attention to people with this serious illness.

These are not cures, they are treatments and they are unsatisfactory. We want to go on and go further. They certainly were beginnings. The Nation's priorities and the Government's role shifts.

In the late 1960's and early 1970's, there was a great deal of focus on things like community mental health centers. Again in the late 1970's, we began a new child, a mental illness and disorders branch. We emphasized brain research and tried to get more of a greater focus on clinical research as opposed to a variety of more difuse social issues often more tenuously related to mental health.

In the last few years, there has been a reorganization with a substantially enhanced schizophrenia research branch. A new intramural laboratory focusing on schizophrenia is now taking shape. Both the intramural and extramural research portfolios of schizophrenia researchers will continue to utilize a variety of sophisticated and advanced techniques, such as imaging, molecular genetics.

The focus will be on neurotransmitters and receptors to advance our understanding of this disease. Two new clinical research centers have just been instituted to support research on schizophrenia.

I think one of the things we can take heart from is that it is a particularly exciting time. I would say, to be a scientist related to brain and their relationship to behavior is as exciting as any field of health research today and that has been documented and articulated by people such as Louis Thomas, as a review of all of the Astor awards in the last 40 years.

Equally important, however, is the need for some essential focus, you have got to have some Government focus which really attends to these disorders. I think it should be greater and with more support than it has been, certainly, in the past. I think we will need some place where this all comes together.

With regard to specific recommendations, if I could just summarize some of the main points I would make to you, first of all, I think there has to be a dramatic increase in the support going to research on schizophrenia.

Second, I think there has to be attention to ways of getting more clinical researchers, more young researchers, and more people with outstanding basic science technologies, to apply them to the disease.

We need to give them the support, we can't have researchers worrying from moment to moment whether their funding is going to be there for them to continue their project. We need to enhance the idea of centers of excellence, where we can get enough people together from the various disciplines in order to really make an attack on the disease.

We need some research focus earlier in students training to get them turned on to research and not be seduced away into clinical careers and careers often with people with less serious illness.

We need a continued attention to rehabilitation and some of the various strategies to help people stay out of hospitals and function better in the community. We need greater public education, and I might add, that there have been a number of cooperative endeavors between professionals and citizens, American Psychiatric Association, NAMI, Mental Health Association, to get information to the public, the Congress, and I think we should see more of that.

There should be as much as possible of partnership and a focus on what we can do, because I think the scientific opportunities create an unusual possibility. This should not only be focused at the Federal level. The Federal level is critical and we need a much dramatically increased boost, but there can also be support at the State level, at the local level, and at the private level.

One of the nice developments is that the citizen organizations in conjunction with the professionals have formed a new organization called the National Alliance for Research on Schizophrenia and Depression, and we intend to try to get private money to complement public money, so we are not simply looking to the public exclusively in this regard.

One of the tragic realities, which I think Senator Weicker was pointing to, is that our priorities have not necessarily put this, nor often some of the other health issues, where they should be on the Nation's agenda. For example, there are something in the neighborhood of a few hundred people doing focus research on schizophrenia. There are some 5,000 on cancer, and we are a happy fourth, but there is a projection that there is going to be some 18,000 doing research on star wars. We think given those kinds of figures, the obvious need for a dramatic increase in those doing research on schizophrenia is critical.

Also, I would add, not only do we need research, but we have to make sure that the services system is adequately supported, and often that requires appropriate coverage for the services costs, coverage comparable to what goes on in general health.

One of the problems is that many people do not have any kind of mental health coverage and often their treatment is interrupted because they have no coverage. Sometimes the providers are held responsible because they can't help given the fact that there are just no funds for it.

I think this is an exciting hearing, a tremendously good time to bring the various forces, Government, policy leaders, citizens, professionals, families, and expatients, all together to finally say, we are going to get after this disease once and for all, together. Not to focus on critiquing one or other groups within that, but really making it a team effort and taking advantage of the fact that the science in this field has never been more exciting, to enable us to really have some hope that we can accomplish something on this disorder.

PREPARED STATEMENT

Senator D'AMATO. Thank you. We will place your statement in the record at this point.

[The statement follows:]

STATEMENT OF HERBERT PARDES

Mr. Chairman, I am Herbert Pardes, M.D., Chairman of the Department of Psychiatry at Columbia University and Director of the New York State Psychiatric Institute. I am also a former Director of the National Institute of Mental Health- the Institute committed to the development of knowledge about, and approaches to, the causes, diagnosis, treatment, prevention and control of major mental illnesses, including schizophrenia. I am honored to again appear before the Committee as Vice-President of the American Psychiatric Association, a medical specialty society representing over 33,000 psychiatrists nationwide, and appeal to you for support in elevating mental illness and schizophrenia research to top priority status as recently recommended by the Institute of Medicine of the National Academy of Sciences. This committee has a strong history of responding favorably to our appeal which is shared by the family and citizen groups appearing with me today.

Mr. Chairman, the APA has developed a fact sheet about schizophrenia which I ask permission to insert into the hearing record. For purposes of summarizing let me say that schizophrenia, while not the most common mental illness, is the most costly and devastating. Cost estimates in the United States alone range upward from $20 billion annually. While, drug and psychosocial treatments have now reduced the burden of the illness on most of the 1.4 million Americans who suffer from it during a given six-month period, improvement is still slow and erratic. Nearly 20 percent of those afflicted still either experience no improvement or develop adverse side-effects that make continued drug treatment impossible. Schizophrenics continue to occupy 40 percent of the Nation's' mental hospital beds -- more than 100,000 people on any given day. Few other mental illnesses disrupt the whole course of their victims' and their families lives so completely. Schizophrenia typically strikes men in their late teens or 20's and women perhaps five years later, just at the point where the victims have finished the long, costly preparation for life and are embarking on adulthood. For reasons that are unclear, but could be related to hormones, the course of the disease is often less severe in women. For the millions of Americans afflicted and the families and friends who suffer with them, the only hope lies in an expanded research effort. I want to emphasize that this tragic illness is devastating to not only the persons afflicted but also to their families.

Schizophrenia, a disabling constellation of mental disorders, has been a central focus of the National Institute of Mental Health (NIMH) since its inception. Schizophrenia is not a simple, or even single illness, rather it is a heterogeneous set of disorders with manifestations which are behavioral, psychological, cognitive and emotional as well as physiological and anatomic. There is now widespread agreement among leading scientists and clinicians that schizophrenia is associated with disturbance in brain physiology. Specific causal factors and treatment measures must be actively investigated through research. Means of identifying causal factors and treatment measures are underway, but hampered severely by a lack of resources, both in personnel and in funding.

Today, a great deal of frustration and concern has been raised about the failure to find cause and cure of this illness, frustration heightened by tantalizing breakthroughs in other illnesses. The truth is that schizophrenia -- the schizophrenias -- are not unlike the cancers. They are difficult illnesses with etiology and course which may differ from patient to patient; the patients because of the disease are difficult patients, are difficult to engage in research; the treatments -- both psychopharmacologic and behavioral -- are difficult to manage, and unpredictable in their effect upon any one patient. Yet there is a further frustration for those both working in and watching for progress in schizophrenia research which does not exist for those working and watching in cancer research: the volatile instability of funding to support the research endeavor.

A "war on cancer" was declared and funds began and have continued to flow to basic, clinical and applied research, and to treatment. No war has been declared on schizophrenia, nor on any of the severe and often chronic mental illnesses; no infusion of funding has flowed to spur those in the schizophrenia research field.

Yet, a small underfunded battle for new knowledge of schizophrenia has been waged by the NIMH. The NIMH's expertise, ranging from brain to behavior, from research laboratory to community, has made it uniquely qualified to address this multifacted illness in all of its dimensions. The NIMH is to mental illness, to schizophrenia, what the National Cancer Institute is to cancer. The researchers -- both intramural and extramural -- cutting across basic and clinical research -- have the biomedical and behavioral background and expertise to conduct what may become the breakthrough research in these fields. Those funded by the NIMH research programs not only have the expertise, but the access to patients to participate in clinical research endeavors, in drug trials, in innovative treatment research efforts. Indeed, through NIMH-funded research have come the two major strides in the management of the schizophrenias: the development and refinement of pharmacological interventions and the creation of multifaceted, multidisciplinary psychosocial rehabilitation programs. /Together, these have provided the means to an enhanced quality of life for many diagnosed schizophrenics.

They are not cures, but treatments which may alleviate symptomatology and permit improved functions, as NIMH struggles to forward basic and clinical research knowledge of the disorders.

In the past few years an even greater emphasis upon the etiology, course and treatment of these illnesses has been mounted, notwithstanding increased economic constraints. Within existing budgetary limitations, the NIMH has rededicated substantial resources to schizophrenia research, mounting an initiative across extramural and intramural research, training and public awareness.

The NIMH's reorganization in late 1985 established a new Schizophrenia Research Branch, now with a staff complement of 13, nearly double its size a year ago. At the same time, a new intramural research laboratory focusing on schizophrenia is taking shape. That laboratory, housed on the NIMH campus as is the entire NIMH Intramural Research Program, will bring the talents of both full-time PHS commissioned staff as well as visiting researchers, research trainees, and -- through collaborative arrangements with the NIH -- other basic and clinical researchers to bear on these disorders. Both the intramural and extramural research portfolios of schizophrenia researchers will continue to utilize sophisticated imaging techniques to further examine the structural brain abnormalities in schizophrenic patients, to delineate the extent to which early cognitive deficits are a basic for identifying children at high risk for schizophrenia, to identify the range of specific psychotherapeutic interventions and medications which are the most effective in treating those now suffering from schizophrenia.

Through careful husbanding of its existing limited research resources, the NIMH has achieved a nearly 20 percent increase in funds increase has supported the establishment of two new clinical research centers focused exclusively on schizophrenia. These "centers of excellence" can help draw current talent as well as help ensure a future generation of schizophrenia researchers. Their emphasis is multi-dimensional, spanning a variety of disciplines and approaches in the quest for increased understanding of this disorder. The number and quality of extramural awards directed toward schizophrenia research in each of the three NIMH Divisions -- basic, clinical and epidemiologic, have been increased by more than 10 percent. Increases in the number of awards to research trainees working in schizophrenia have also been noted.

The types of research to be undertaken to unlock the Pandora's Box of schizophrenia will require attention to the basic science areas of molecular genetics; to neurotransmitters and systems of neurotransmission; to viral and autoimmune systems; and to the emerging field of molecular epidemiology. Increasing emphasis must also be placed on clinical research areas: finding pharmacologic agents which will serve the needs of those patients for whom neuroleptics are not appropriate; developing new antipsychotic drugs and new models for drug screening. Existing treatment mechanisms -- such as the psychosocial rehabilitation programs discussed previously -- can be amplified and further improved.

Equally central is the need for a focal point for the biomedical and behavioral research in schizophrenia. While countless researchers, institutions and Federal agencies may share in the quest for knowledge, we believe the NIMH should continue to serve this critical integrative function. It stands as the single Institute across ADAMHA and the NIH dedicated to the study of serious mental illnesses, in research, in treatment, in service delivery, and in public awareness. It can and should continue in this function, and should be provided the resources to wage not a series of battles, but an outright war against the devastating illnesses called schizophrenia.

Finally, Mr. Chairman, an expansion of the role of the Federal research establishment in the area of schizophrenia is critical if we are to attract young researchers to this field. This issue of recruitment and retention of research scientists was the focus of a recent 1985 NIMH consultants' meeting at which time the nation's leading investigators expressed grave concern about the recruitment problems. Given the long pipeline of research training leading to an independent research career, the attendees were unanimous in assuming that the situation will worsen significantly over the next decades unless something is done. It was — and is — deemed imperative that this shortfall of well-trained research personnel be addressed immediately to prevent further irreparable damage to future research efforts.

Mr. Chairman, thank you again for this opportunity to appear before you and I would be pleased to answer any questions.

Senator D'AMATO. Doctor, do you think that the additional infusion of dollars into schizophrenia research would be sufficient to counter the problem or are there other obstacles to overcome as well?

Dr. PARDES. Absolutely. I think, first of all, one has to get the national leaders, and again I am very appreciative to Ms. Van Devere, because what we need is people with name recognition to go out and say that this is a serious illness that needs to be attended to.

There are others who have also taken the opportunity, but if you think about it for a moment, if you gather 10 or 12 people in a room and said we had $1 million of research moneys to dispense, what should we give it to, should we give it to cancer, heart disease, or schizophrenia? Most people think they may get cancer, most people think they may get heart disease, nobody thinks they are going to become schizophrenic.

As a result that kind of decisionmaking has purveyed the allocations of support moneys on this issue. So you need public education, you need professional organizations, such as the psychiatric organization to push this as a major priority, which we intend to do.

You need professionals, and citizens joining together to say how can we make the treatment system better, how can we make sure that whatever resources are being used are being used well.

Still, I would say, not to attend to the fact that the NIMH total budget for teenage suicide and manic depressive disease and hyperactive children, and schizophrenia, and Alzheimer's disease, is something in the neighborhood of $248 million, that is a pittance when one thinks of the enormous number of diseases, so one needs more resources, more public education, more of a team effort. I think there are a variety of things that have to be done, not only money, but money is important.

Senator D'AMATO. Let me ask you as an aside, would you be in a position to give an estimate as to the percertage of people who find themselves homeless? We, back in New York, see this phenomena with an increasing degree of severity and it is not one that is indigenous just to New York.

What percentage would you estimate have mental illness, whether it be schizophrenia or any other form of mental illness?

Dr. PARDES. Whatever data there is on this is very much varied, it changes from place to place. I would say the likelihood is that one could assume that no less than 25 to 50 percent of such people have some kind of psychiatrical, mixed psychiatric and substance abuse, problem.

Senator D'AMATO. Anywhere from 25 to 50 percent?

Dr. PARDES. I would say that as a rough estimate. The studies have varied, but your point that this is a substantial problem, a substantial part of the homeless question. To be careful on the homeless question, I think, there is a whole other cadre of people not with those illnesses and that, I think, gets into the question of available housing, which is a major problem.

Senator D'AMATO. But the problem of homeless is exacerbated tremendously by those who, then, have this affliction in addition to the dealing with the lack of housing in various areas, this just exacerbates that problem tremendously.

Dr. PARDES. Absolutely.

Senator D'AMATO. For these people, obviously, treatment becomes a prerequisite and that is one of our great problems, it seems to me.

Dr. PARDES. I think that when one thinks about the population of homeless people, that we should think about the various kinds of problems that they have, and develop services tailored to what they need. Not all of them need mental health services, a substantial component do, some of them need, primarily, a housing service, some of them need a combination of housing and other social supports, and have no problem related to mental illness as such, some of them are primarily suffering some of the ravages of alcoholism or other drug abusing problems, some of them are mixtures.

I think of this issue being similar to when we want to take a look at a large problem, and desegregate and then develop strategies that relate to the specific subtypes. I think that is what is going to happen in schizophrenia, as well. For example, mental retardation, which is a major disorder in this country, often has a final common path which may look very much alike, but it is caused by probably 100 different contributing disorders.

I think there are a number of things that contribute to homelessness, I think there are a number of things that contribute to schizophrenia.

Senator D'AMATO. Let me ask you another question. Do you believe that there is really a hope of finding a cure for schizophrenia, or a treatment that does more than just suppress the more visible manifestations of the disease?

Dr. PARDES. I think that there is definitely a hope. The problem for researchers is to both bring the excitement when research offers a possibility, but to caution that one can never predict the way research will go. It is just not the same as being able to say you are going to do this job, produce this number of cars.

I think that the excitement right now is in molecular genetics. Certain major research laboratories are trying to blend molecular genetics and the issue of concern is the increasing understanding of how the brain functions, how the various cells communicate with each other, how they affect things like memory, learning, affect, pain.

I think the fact that we are getting an increasing understanding, offers me the hope that we may really be able to crack it, but there is a tremendous job out there to be done, and you are going to need much more than the handful of people working on it right now.

Senator D'AMATO. Doctor, I thank you, not only for your testimony today, but for your leadership in this area, and I look forward, certainly, to working with you.

Dr. PARDES. Thank you, Senator.

STATEMENT OF DR. DALE L. JOHNSON, PROFESSOR OF PSYCHOLOGY, UNIVERSITY OF HOUSTON, REPRESENTING THE AMERICAN PSYCHOLOGICAL ASSOCIATION

Senator D'AMATO. Our next witness is Dr. Dale Johnson, professor of psychology at the University of Houston.

Dr. Johnson, you have long been involved in research on schizophrenia and you appear before the subcommittee today representing the American Psychological Association. Welcome and we will take your remarks as if read in their entirety, and if you would care to highlight any aspects in them, or point out any other areas, I would be delighted to receive that additional testimony.

Dr. JOHNSON. Thank you, Senator D'Amato. Thank you for the opportunity to appear before the committee today.

I am a psychologist, and I would also like to mention that I am a member of the board of the National Alliance for the Mentally Ill. As a psychologist, I am a researcher, teacher, and clinician, and that is not unusual for psychologists, but I am also the father of a schizophrenic son. That is a somewhat unique situation.

My wife and I saw our delightful baby enter childhood eager to meet the world, and full of expectations for his future, become crushed by the dreadful illness of schizophrenia. Now, 14 years later, he struggles daily to find some sense in life.

I travel a good deal, and have met hundreds of people with schizophrenia, and their families in the last few years. I find that our situation is not at all unusual, it is commonplace. As I look around the United States, I think the condition of the mentally ill is deplorable. It is truly awful.

The precise causes of schizophrenia are not known. Many researchers agree, however, that the disorder results from a complex combination of genetic, social, and psychological factors. Some people may have an inherited vulnerability to schizophrenia. Children with a schizophrenic parent are 10 times more likely to suffer from the disorder than the general population. Still, 90 percent of the children of a schizophrenia parent do not develop the condition.

Important research is being conducted by psychologists in trying to identify why some children are at a high risk of developing schizophrenia and others are not. Other psychologists are also looking at how the brain of a schizophrenic processes information differently from a brain of an individual without the disorder. It is becoming increasingly clear that social and psychological factors may serve as catalysts in those individuals who develop the disorder.

In the past families have often been unjustifiably blamed for causing this disorder and I have very definitely. Now it is clear that supportive families are an integral part of the recovery process. For example, there is strong evidence that unmanaged stress can trigger the disorder in these vulnerable individuals.

Psychologists are working with recovering schizophrenics and their families, helping them to develop effective methods of dealing with everyday stress. The education of families in the area of stress management can also serve as a preventive intervention to reduce otherwise high levels of anxiety and depression among the family members themselves. More support for such stress management research is needed, as a major step toward preventive measures in schizophrenia.

Schizophrenia is, in most cases, lifelong and the course is too often marked by a series of psychotic episodes from adolescence on. It is widely acknowledged that medication alone is not enough to prevent relapses and to improve the functioning of a schizophrenic in the community.

Many psychologists and other mental health professionals have been most encouraged by the results of carefully designed treatment and rehabilitation programs, which have been derived from basic research on learning and social functioning and which incorporate behavior strategies and medication, such programs reduce the length of hospitalization, as well as significantly reduce the rate of relapse after the recovering schizophrenic returns to the community. More of this research is needed and research of the problem of noncompliance with pharmacological treatment.

Encouraging evidence shows that a treatment program based on social learning principles can be reducing and rehabilitating schizophrenics, such programs consist of teaching the schizophrenic many of the skills needed in day-to-day living before they reenter the community and while they are in the community. Five years after the beginning of one such program, 97 percent of the patients were in the community and doing quite well.

Research on vocational assessment and rehabilitation indicates that large numbers of people with mental disorders tend to be rehabilitated, and more research is needed in this area. It is also likely that focused research on neurological development in adolescence along with the behavioral correlates and processes of coping with these changes by the adolescent and family, will lead to effective early treatment and we would hope eventually prevention.

After a normal childhood, my son began showing symptoms when he was 17, and was psychotic when he was 19. Today, although improved, he is still quite disturbed. The possibility of the prevention of schizophrenia in adolescents, of the kind that he has suffered, appeals to me greatly, as both a scientist and a father, because schizophrenia is such a long lasting disorder and is so tremendously disabling, and because most schizophrenics live not in hospitals but in communities, it is imperative that comprehensive, coordinated treatment and rehabilitation programs be put in place, such programs now exist in only a few communities in the United States.

Widespread implementation of the programs I have described so briefly, would be highly cost effective, and even more important will result in a better quality of life for those citizens afflicted with schizophrenia and their families.

They are so cost effective that I wish that there were a golden something or other award for federally funded projects that do not fleece the public, but actually return a magnitude of benefits to the public. I think Bill Fairweather's Lodge Program is one candidate for such an award.

PREPARED STATEMENT

I have a long list of urgently needed research, which I will not present at this time.

[The statement follows:]

STATEMENT OF DALE L. JOHNSON

Mr. Chairman and Members of the Committee. My name is Dr Dale L. Johnson, and I am Professor of Psychology at the University of Houston. I am pleased to be here today to testify on behalf of the 87,000 members of the American Psychological Association. I am also a member of the board of the National Alliance for the Mentally Ill.

When the public thinks about research and treatment in the area of schizophrenia, they usually assume that this is the work of psychiatrists. My intention here today was to share with this Committee the breadth of the significant contributions also being made to this field by psychologists, and to emphasize that the entire mental health community is working closely together on preventing this devastating disorder.

My perspective on schizophrenia is unique. I am a researcher and a clinician -- as are many psychologists -- but my perspective is unusual because I am also the father of a schizophrenic son. The experience I have had living with schizophrenia has made it clear to me that there is much more we need to learn about the causes and treatment of this dreadful and complex mental disorder.

As you know, the precise causes of schizophrenia are not known. Many researchers agree, however, that the disorder results from a complex combination of genetic, social, and psychological factors. Some people may have an inherited vulnerability to schizophrenia. Children with a schizophrenic parent are ten times more likely to suffer from the disorder than the general population. Still, 90 percent of the children of a schizophrenic parent do not develop the condition. Important research is being conducted by psychologists on trying to identify why some children are at a high risk of developing schizophrenia, and other are not. Many psychologists are also looking at how the brain of a schizophrenic processes information differently from the brain of an individual without the disorder.

It is becoming increasingly clear that social and psychological factors may serve as catalysts in those individuals that develop the disorder. In the past, families have often been unjustifiably blamed for causing this disorder. Now it is clear that supportive families are an integral part of the recovery process.

For example, there is strong evidence that unmanaged stress can trigger the disorder in these vulnerable individuals. Psychologists are working with recovering schizophrenics and their families, helping them to develop effective methods of dealing with everyday stress. The education of families in the area of stress management can also serve as a preventive intervention to reduce otherwise high levels of anxiety and depression among both schizophrenics and their family members. More support for such stress management research is needed as a major step toward preventive measures in schizophrenia.

Studies also indicate that schizophrenia may also be associated with physical changes in the chemicals and structure of the brain. It is still not clear whether these biological changes cause schizophrenia or are a result of the condition.

Schizophrenia is in most cases life-long and the course is too often marked by a series of psychotic episodes from adolescence on. It is widely acknowledged that medication alone is not enough to prevent relapses and to improve the functioning of a schizophrenic in the community. Many psychologists and other mental health professionals have been most encouraged by results of carefully designed treatment and rehabilitation programs which incorporate behavioral strategies and medication. Such programs reduce the length of hospitalization, as well as significantly reduce the rate of relapse after the recovering schizophrenic returns to the community. More behavioral research is needed, however, in the problems of non-compliance with pharmacological treatments.

Encouraging evidence shows that a treatment program based on social learning principles can be successful in rehabilitating schizophrenics. Such programs consist of teaching schizophrenics many of the skills needed in day-to-day living before they re-enter the community. Five years after the beginning of one such program, 97% of the patients were in the community and doing quite well.

It is also likely that focused research on neurological development in adolescence along with the behavioral correlates and the processes of coping with these changes by the adolescent and family will lead to effective early treatment and, eventually, prevention. After a normal childhood, my son began showing symptoms when he was 17 and was psychotic when 19. Now 14 years later, he is still very disturbed. The possibility of prevention of schizophrenia in adolescence of the kind he has suffered appeals to me greatly as both a scientist and a father.

Research on vocational assessment and rehabilitation indicates that large numbers of people with mental disorders can be rehabilitated vocationally. More research is badly needed in this important area.

Because schizophrenia is such a long-lasting disorder, is so tremendously disabling, and most schizophrenics live not in hospitals but in communities, it is imperative that comprehensive, coordinated treatment and rehabilitation programs be put in place. Such programs now exist in a few communities in the United States. Widespread implementation of the programs I have described so briefly will be highly cost effective and, even more important, will result in a better quality of life for those citizens afflicted with schizophrenia and their families.

What is important about all of these programs I have mentioned is that they were developed in a context of exacting research standards. The research that led to the development of these programs represents the best evidence we have today about how to rehabilitate those people with serious mental disorders.

Senator D'AMATO. Pardon me, if I might do something a little unusual. I do a lot of things unusual—a break in the tradition.

In your draft testimony, you touched on two programs which had achieved immense success. One was the Fairweather Lodge Program and the second is the correlated token economy system.

If you could, briefly, for the benefit of both the record and those who are here, elaborate on those two programs for the committee, and tell us why you think they have not been replicated on a wide scale, given their success.

Dr. JOHNSON. The first, the Fairweather Lodge Program, was developed initially in the Veterans' Administration's hospitals. It involves training mentally ill patients to work together, and to operate their own business, typically a janitorial business, on returning to the community. This they do, and they do it effectively, and they pretty much pay their own way in doing this.

This program has been disseminated rather nicely, largely through the NIMH community support program auspices. There are, at last I heard, about 250 such programs. They need tremendously more support from the public at large for contracts. They are simply asking for an opportunity to do work, and they do the work well, but the stigma of mental illness has interfered with their ability to get these contracts.

The other program, which is Gordon Paul's Social Learning Program, was focused at the subgroup of schizophrenics, who are particularly resistant to medication, they just don't do well until they languish in hospitals. In his study, they have been in Illinois State hospitals an average of 16 to 17 years.

He found that with a carefully structured social learning program, and this when I say careful I am almost underestimating, these people are returned to the community, 97 percent of them back in the community, 5 years after and doing fairly well. These, I think, are programs which give me rise for optimism, but they are limited and they are not appropriate for all of the people that make up this very, very strange mixture of problems we call schizophrenia.

Senator D'AMATO. I just wanted you to touch on those two programs, if you had anything else.

One other question, you stated that a family management approach results in a decreased burden on the family members. Would you elaborate on what you mean by that family management approach, and how are these services made available to a family?

Dr. JOHNSON. When most of us or our family members are hit by schizophrenia, we know nothing about the disorder, or the illness, we don't know what to do. I might add, that applies to clinical psychologists, graduates of good training programs, 10 years functioning as a clinical psychologist, also, I didn't know what to do.

Family management training's professional staff tells families about schizophrenia. It educates them in how to cope with crises, perhaps more importantly, how to prevent crises from occurring. It involves families in the process. More as allies than putting them off to one side and say let us take over, we will manage without you, and then return the mentally ill person to you, usually by surprise.

This kind of a program has been demonstrated, now in several research projects, and another large project that is underway by NIMH at the present time, to reduce relapse rates from something like 50 percent, even with medication, in the 9 months after hospitalization to about 10 percent.

That is an effect, a program effect, that is impressive to anybody who does research on interventions with humans. It is just a very impressive effect.

Senator D'AMATO. Doctor, I want to thank you for your testimony, and for your candor. Often it is difficult to imagine oneself with the problem that you have described, and when you make the point so poignantly, as you do, that even those who are trained in this area have great difficulty in dealing with it when it strikes them personally. I would imagine, those who are totally unsuspecting and are not trained to even recognize the symptoms would have even more difficulty.

Over how long would that take place? You mentioned, for example, your son, what are the kinds of things that someone would look for?

Dr. JOHNSON. It is very hard to say, that is, looking at it just——

Senator D'AMATO. Say, the young adolescent.

Dr. JOHNSON. He was near the top of his high school class, vice president of the class as a senior, went to Harvard. He was doing well in a lot of ways, just remarkably well, and it all came very easy for him.

What we saw as first signs was a kind of withdrawal and an exaggeration of certain normal adolescent nastiness. We said, is it drugs? You know, this was in the last days of Vietnam, et cetera. And indeed, it was drugs. That was part of it, but he said he had stopped the drugs. They were too distressing to him.

We thought and so did other people, including some various astute clinicians, that he would do better, that somehow this would clear up, that was the hope. I would hope now, that our diagnostic procedures would go forward and that we would develop better ways of making this kind of identification.

I think that in doing this we really must look at a bio, psycho, social orientation. This is clearly to me a function of brain and behavior all the way along, and that we do our diagnosis in those terms, I would hope this is possible.

Senator D'AMATO. Thank you very much, doctor.

Dr. JOHNSON. Thank you, sir.

STATEMENT OF LEONA L. BACHRACH, PH.D., RESEARCH PROFESSOR OF PSYCHIATRY, MARYLAND PSYCHIATRIC RESEARCH CENTER, UNIVERSITY OF MARYLAND SCHOOL OF MEDICINE

PREPARED STATEMENT

Senator D'AMATO. Our final witness this morning is Dr. Leona Bachrach, a research professor of psychiatry, at the Maryland Psychiatric Research Institute at the University of Maryland, School of Medicine.

Dr. Bachrach is well known for her research on issues relating to the deinstitutionalization of the mentally ill. She is here today to bring those issues to us, and the public policy questions they raise.

I attempted to some way touch on that before doctor, because I do believe that there is a contributing force to the problem of the homeless, which really exacerbates it tremendously.

It is certainly a pleasure to have you before the committee and, as we have indicated in the past, we will take all of your testimony as if read into the record and it will be incorporated into the record. If you would care to highlight any portion of it, then, please proceed.

[The statement follows:]

STATEMENT OF LEONA L. BACHRACH

Mr. Chairman and Members of the Committee, my name is Leona Bachrach. I am a Professor of Psychiatry at the Maryland Psychiatric Research Center of the University of Maryland School of Medicine in Baltimore. I thank you very much for giving me this opportunity to speak to you about issues in deinstitutionalization that have affected our schizophrenic citizens in the United States. Service planning for severely ill psychiatric patients has been my major research and teaching focus for the past 15 years, and it is a subject to which I am deeply committed.

Mr. Chairman, last summer I was privileged to speak at two major mental hospitals in The Netherlands. I used those occasions to summarize some of my thoughts on deinstitutionalization in the United States. I should like to ask your permission at this time to include transcripts of those presentations in the recorded proceedings of this Subcommittee, as I feel that these documents will serve to emphasize the points I wish to stress in my testimony at this time.

I believe that the past 30 years have witnessed some dramatic progress in the ways in which we plan mental health care and supportive services for our schizophrenic citizens. Our concepts of care and our service delivery systems are in many ways more humane and more sensitive than they have ever been before. However, we have also encountered some serious problems in delivering services to schizophrenic patients, and those problems result from a variety of sources that I'll be discussing in a moment.

I think that it's important for us to understand, and to emphasize, both our successes and our problems, as we attempt to improve our systems of care. However, it is sometimes difficult for us to acknowledge the problems. Those of us who are involved in planning services for schizophrenic patients are all too aware that the gains that we have made have been hard-won, and I believe that we have some fear that we may undermine those advances if we stress our difficulties too much and fail to advertise our successes in community-based, or deinstitutionalized, care for schizophrenic patients.

So I want to begin by making it very clear that in those communities where deinstitutionalization has worked, it has often worked very well indeed. There is little doubt that where a full range of community-based alternatives to institutional care can be implemented, people who have schizophrenia, many of whom would otherwise spend lifetimes of despair in institutional settings, have led more hopeful and more fulfilled lives. I would not discourage our quest for improving community-based services for members of this patient population.

At the same time, however, I would stress that not all of our schizophrenic citizens have benefitted from our new initiatives in service delivery. In 1955, a little more than three decades ago, there were 560,000 people who lived as residents of our state mental hospitals. Today, that number is about 114,000. These 114,000 resident patients represent approximately 6 percent of our schizophrenic citizens. Where are the other 94 percent? Some of them, of course, are functioning successfully as members of communities. Some are enrolled in community-based outpatient or day treatment facilities and are receiving high-quality care. But the sad truth is, that although we can account for some of that 94 percent, a substantial portion of the total eludes us on any given day. We often do not know where these people are, or even who they are, even when they desperately need our help. Some of them are living on our streets and are totally unserved by our mental health service systems.

These people are our neighbors, our friends, and our family members. They are people with severe illnesses who are often gravely disabled. They are, I would submit to you, people who, because their disabilities can be so consuming and so severe, desperately need our assistance. However, they typically encounter major barriers to care in our service systems.

A first isssue major issue in serving schizophrenic patients that I would call to your attention has to do with the complexity of the patient population. The move toward community-based care in the United States has profoundly changed the nature of the population of schizophrenic patients. Never before in our history have we had so many different kinds of individuals who need our assistance. Some people who are afflicted with schizophrenia have been released from state mental hospitals after as many as four or five decades in residence. But other individuals, who may be just as sick, are being denied admission to state mental hospitals in the first place, and some of them spend absolutely no time at all in state mental hospitals. In fact, in some communities in the United States today, the number of people who have schizophrenia who have never been institutionalized probably exceeds the number who have ever been institutionalized.

Of those patients who have been released from state mental hospitals, many have been shunted to places that we really should call "mini-institutions" -- facilities where, by almost any measure, the quality of life for these individuals has actually deteriorated. Other released patients have shown a persistent dependency on institutional care, and they have developed patterns of repeated readmission and discharge -- what we call the "revolving door." And, meanwhile, substantial numbers of patients have remained inside state mental hospitals. These are patients who, even in an era that idealizes the benefits of community-based care, are considered to be poor risks for discharge.

Now, this splintering of the population represents a major change from what occurred in the days before deinstitutionalization. In those days, we largely had the illusion that all schizophrenic people needed the same kind of thing -- placement in a state mental hospital. So people with schizophrenia were admitted to institutions, and they usually stayed there for a very long time -- often for the rest of their lives. Individuals differed very little in their treatment histories and their residential histories, and they were thought to be fairly uniform in their treatment needs.

But in today's system of care, we have lost the illusion of uniform need -- one of the plusses of deinstitutionalization. Today's schizophrenic patients differ tremendously. They differ in their functional levels; they differ in their diagnoses; and they differ in their treatment histories. And they all need different kinds of programs.

So, a major issue in planning services has to do with the complexity of the patient population, and with the fact that our imagination and our creativity -- to say nothing of our pocketbooks -- have not always been equal to the task of responding to that diversity. It seems that we no sooner find solutions for one segment of the population -- for example, "aftercare" services for people who have spent long periods of time inside institutions -- than we become aware of other segments whose needs we have overlooked -- for example, young adults with schizophrenic diagnoses who have spent no time at all inside institutions and who, instead of needing "aftercare," simply need to be engaged by the service system in the first place. Many of these younger patients, who are not the products of years of institutional residence, are immensely difficult to reach.

The second major issue in deinstitutionalization that I would mention revolves around difficulties that we have in providing continuity in the care of this patient population. The service needs of schizophrenic individuals tend to endure over time, even though in the early years of deinstitutionalization, many people considered that, without the negative effects of institutional residence, chronicity would somehow disappear.

But even though the disabilities and the service needs of schizophrenic patients often persist over time, service planning tends to focus on their immediate requirements and to ignore the future. An Illinois psychiatrist named Norris Hansell has written that we plan services for chronic mental patients as if they are "single-episode" users of services; and we virtually ignore the reality that these patients will, for the most part, be extensive users of services over long periods of time. In short, we are very much missing longitudinality in our service planning.

A third difficulty -- the third major issue in deinstitutionalization that I would mention -- is that, in addition to problems with continuity of care, we also have had problems in providing comprehensive care to schizophrenic patients. These patients -- precisely because of their illnesses and their disabilities -- tend to need a whole variety of psychiatric, medical, social, rehabilitative, vocational, and quasi-vocational services. They also often need something that can be referred to simply as sanctuary, or safe haven, or asylum -- just as political refugees, or even you and I, sometimes need safe haven: an escape from the pressures of the world. Sometimes, people who have schizophrenia need this kind of safe haven or asylum temporarily, until a crisis can be resolved; sometimes they need it more or less permanently. Every patient must be evaluated for this, as for everything else, on an individual basis. And I would add parenthetically that we know from some of our successful programs that we must not confuse the function of asylum with a place that we call an asylum. It is possible -- often difficult, but possible -- to provide the function of asylum in smaller, community-based short- or long-term treatment settings.

Now, in the past, providing comprehensive care, including the function of asylum, was relatively easy to do. Most people who had schizophrenia were admitted to state mental hospitals, where they tended to stay indefinitely; and virtually all of the services that they needed could be arranged within that single physical setting. We may not always have liked what happened inside those institutions -- but at least all of the services that patients needed were localized in one place. And that counted for something.

But, of course, things are different today. Today, the authority for providing services to schizophrenic patients is divided. It's divided among many health and human service agencies in the public and private sectors. And successful programs depend upon the fine tuning of initiatives that originate with separate, and sometimes competing, authorities. To use a cliche, our service system is often hopelessly fragmented.

A fourth issue in deinstitutionalization revolves around patient selection and gatekeeping. We now know that many efforts that are ostensibly designed as deinstitutionalization programs in fact resist treating the most severely disabled patients. Community-based programs often focus on the needs of patients who are, in the words of two psychiatrists, Jack Zusman of Florida and H. Richard Lamb of California, "healthy but unhappy" individuals. Our early efforts at community-based care simply often failed to assign priority to the needs of the most severely ill people. And the result is that these individuals, who often cannot advocate effectively on their own behalf, are frequently totally unserved. The system of care has instead gone on to serve other individuals who have greater relative ease in accessing services. And many concerned mental health professionals today deplore the deflection of community resources toward patients with less severe disorders, at the expense of those patients who are most disabled and least able to compete successfully for scarce services.

Finally, the fifth issue in deinstitutionalization that I would call to your attention is that the delivery of community-based services to schizophrenic patients continues to take place against a backdrop of stigma that's been exceedingly difficult to penetrate. Neither the successes of some of our very good "model" programs in delivering community-based care, nor the active and growing concern of patient advocacy groups, has succeeded in bringing about the revolution in the public's thinking that ideally was going to accompany deinstitutionalization. And the public -- and often even members of the mental health professions -- continue to stigmatize people who are chronically mentally ill. The positive social sanctions that would encourage us to respond to the needs of people who are chronically disabled have simply not fallen into place.

So to summarize where we are today, there seem to be at least five major kinds of issues that affect service delivery for schizophrenic patients in deinstitutionalized service systems. These are concerned with the complexity of the population, with continuity and comprehensiveness of care, with gatekeeping, and with stigma. All of these issues need to be addressed -- all of these problems need to be heeded -- as we attempt to lend support to the positive effects of deinstitutionalization and to counteract some of its negative fallout.

I thank you for giving me this opportunity to share these concerns with you, and I shall welcome the opportunity to try to answer any questions that you may have.

CONTINUITY OF CARE*

Leona L. Bachrach, Ph.D.**

Thank you for your kind invitation to me to speak about continuity of care for chronic mental patients in the United States. It's a great pleasure for me to be here with you today, and my husband joins me in telling you how much we love The Netherlands. This is our second visit, and we feel very welcome, very much at home.

I'd like to begin my comments by pointing out to you that in the United States our psychiatric service system is truly pluralistic, in every imaginable way. Depending on where in the United States a patient lives, he or she may find that psychiatric services are offered by the local government or by the state government, or by many different health and social service agencies that are privately owned and operated -- agencies that are not under governmental control. Sometimes, in some communities, there are no psychiatric services at all. But usually, in any one community, a combination of governmental and private services is offered. And, in every one of our 50 states, the specific pattern of organization is just a little bit different.

The word that we sometimes use to describe this situation is "fragmentation." You often hear people saying that our psychiatric service system is very fragmented: it is broken up into many parts, so that a patient may go to one place for medications, to another place for vocational rehabilitation, and to still another place to eat and maybe another place to sleep.

Because this is true, the patient -- who is likely, of course, to be very disabled as the result of his or her illness -- often needs help in putting the pieces of the service system together. In other words, the patient must have ready access to all of the many services that are required

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for treatment and rehabilitation -- and this is what we call continuity of care. Continuity of care means that the patient will be able to receive all of the different services that he or she needs, even though the service system is fragmented, and even though many different service delivery agencies must be involved in his or her treatment (Bachrach 1981).

Now, I would like to mention that the whole idea of continuity of care became popular in the United States in the years immediately following World War II. It was an idea that people talked about in all branches of American medicine, not only in psychiatry. And I want to make it clear that continuity is difficult to achieve in *any* kind of medical care, because of some distinctive cultural features of American life. We are a pluralistic society, as I pointed out a moment ago; and the resultant fragmentation makes continuity rather difficult to achieve. But continuity is most particularly difficult to attain for people with chronic mental illnesses.

Continuity of care means that the service system must be *accessible* to the patient -- accessible in several different ways. First of all, there must be *psychological* access. The services must be offered in such a way that the patient will not be frightened or upset by the intervention.

Second, in addition to psychological access, there must also be *financial* access. The patient must be able to pay for the services. And this can be a considerable problem in a country where there is no universal entitlement to health care, and where it may be very difficult for a patient to be placed on the roles for federal disability insurance payments.

Third, the services must also be *geographically* accessible. The patient must be able to reach the location where the services are provided. And this can also be a considerable problem in the United States, because the distances in some communities in my country are so very great.

And, finally, particularly for a patient who is chronically ill or disabled, the services must be accessible over *long periods of time*. And this can be particularly difficult for us in the United States, too, as we often tend to plan for short-term solutions and to eschew long-term planning (Hansell 1978).

Now, at about the same time that the notion of continuity of care was becoming popular in the United States, something else was happening that complicated the delivery of services to chronic mental patients. We were at that time beginning to deinstitutionalize our psychiatric service system -- that is, we were starting out on a very dramatic shift in the place where the major portion of psychiatric care was to be delivered. We were moving rapidly away from caring for mental patients primarily in large state mental hospitals to caring for them primarily in community-based settings.

Deinstitutionalization has had different kinds of effects on chronic mental patients throughout the United States. For some patients, the process has been a very beneficial one, but for others it has been exceedingly troublesome. It seems as if deinstitutionalization has given us the potential for improving services. We can now offer many programs to patients that are more creative, and more imaginative, and more responsive to their specific needs than what was offered to them in former years. But, at the same time that the potential is there, access to the service system has become more difficult than it used to be. In the days before deinstitutionalization, virtually all services for these patients were contained in one single physical setting -- the state mental hospital. Now, with deinstitutionalization, fragmentation has become a serious problem, and continuity of care has become severely compromised.

We are now finally beginning to understand the seriousness of this situation. It appears that our community-based replacements for long-term state hospital care have not always been as effective as we had hoped that they would be. Many of our patients find themselves having severe problems as they try to navigate through our complex systems of care, and often they cannot do so without special assistance. Some of these patients, in fact, are so helpless that they don't even know where or how to apply for help. And in many ways these patients -- the ones who have the most difficulty in asserting themselves -- are in worse circumstances today than they were in the days before deinstitutionalization.

We have all of these problems in the United States today, and I don't want to underestimate their prevalence. Deinstitutionalization, basically a humane and patient-oriented philosophy (Bachrach 1983a), has often been awkwardly, or even poorly, implemented in many parts of my country. And, although it is a policy that has potential, that promise has not always been fulfilled.

However, I believe that our problems with deinstitutionalization are teaching us some important things. We are now making some progress in identifying what we need to do in order ensure that chronic mental patients living in the community have continuity in their care. And I would like to talk about some of the elements that we have come to acknowledge.

I would say to you that continuity of care is facilitated when the following kinds of programs are provided: crisis stabilization services, residential alternatives, treatment settings, treatment services, and transportation services (Bachrach 1983b). These are the interventions that we now understand that we must offer, and I would like to spend a few moments discussing each of them.

Crisis Stabilization Services

We now understand that community-based systems of care for chronic mental patients must offer crisis stabilization services. This is an acknowledgment that many chronically mentally ill individuals undergo crises that require immediate attention. And, in order to respond to those crises, programs must be available to them on a 24-hour basis: they must be open around the clock.

Crisis stabilization subsumes several different kinds of care for chronic mental patients. Sometimes it means providing them with rapidly initiated doses of medication. But medication cannot be the only kind of crisis intervention; it must be supplemented by other services. Dr. John Strauss (1980) of Yale University has written that, for some of these patients, the use of medication may even contribute to chronicity, apparently by reducing their motivation and by limiting their sense of control. Accordingly, we must also be ready to provide crisis residences, crisis counseling, and crisis beds in community hospitals in addition to (or sometimes in place of) medications, in order to ensure that these patients have the wherewithal to overcome their acute situations.

Residential Alternatives

In addition to crisis stabilization services, a community-based system of care for chronic mental patients must provide an array of residential alternatives. In fact, there is widespread agreement today that having a comprehensive network of residential services is one of the most fundamental elements in a system of care for these individuals. It is absolutely basic to their survival in the community.

Ideally, the network of residential services should contain several different kinds of housing alternatives to meet the diverse needs of members of the patient population. For example, it should include a variety of out-of-hospital living environments, such as halfway houses, long-term group residences, supervised apartments, foster care or family care homes, nursing homes, and board-and-care homes (American Psychiatric Association 1982). All of these different alternatives have been widely discussed in the American literature, and I shall not, with our limited time, go into a description of them today.

However, I'd like to make several important points regarding the provision of residential alternatives. First, it's not enough for the system of care to provide only community-based housing. The system also must provide, for some chronic mental patients, in-hospital residential alternatives, where treatment services are provided under the same roof as residential services. I'll say more about that in just a moment.

Secondly, I want to note that the permutations and the special arrangements in residential programming can be very innovative, and that some of the most basic and creative planning for chronic mental patients involves the development of residential services.

And, third, I want to note that, over the years, I've come to appreciate the fact that the outward appearance of a residential facility is not the most important thing about it. Much more critical is what happens inside. I have visited many beautiful residential settings throughout the United States, and it is quite heartening to see those places. But I have also learned that humane and therapeutic things may happen in less attractive facilities, too -- and that we must not always defer the development of residential services until we have the money to construct something of great architectural beauty.

I believe that residences for chronic mental patients must strive, as best they can, to feel like home: not always handsome, but a place to belong -- even a place to which a patient may return if he or she must leave for a few days in order to return to the hospital, or for any other reason. That is frequently a major problem in the United States, because, very often, when a patient goes away for a few days, he or she gives up his or her place in the residential facility.

Treatment Settings

But, of course, we're talking now about people who are, generally speaking, very disabled, so something more than residential alternatives must be provided for them. In addition to residences, they also require treatment settings -- that is, places in which treatment takes place, as distinct from places in which they live. In the United States, we often confuse these two things -- residential alternatives and treatment settings. And what we've often done is change a patient's residence from the state mental hospital to a community-based facility but then effectively forgotten that that hospital also serves other -- that is, nonresidential -- functions. Specifically, the state hospital traditionally stands as a place that is both a residential alternative and a treatment setting.

So, just as the service system must provide a variety of residential alternatives, so must it provide an array of treatment settings. It must ensure places for inpatient care, outpatient care, and partial hospitalization. And, in some cases, patients will also benefit from home care which, whenever possible, should be added to the range of available treatment settings.

I'd like to note parenthetically that our attitude toward inpatient care is still evolving in the United States. The polarized anti-hospital stance that characterized the early years of deinstitutionalization is giving way today in many quarters to an increased sense of the important role that hospitals may play in the care of at least some chronic mental patients. In the early years of deinstitutionalization, admission to a hospital in the United States, particularly a state mental hospital, was considered to be evidence that the service system had somehow failed. Today, however, the hospital is increasingly being seen as a positive alternative among treatment settings for some patients at some times, as it often is in the case of patients with chronic nonpsychiatric illnesses.

What is more, different varieties of inpatient settings are called for in a complete system of care, and they must range from places that provide overnight stays to those that allow for more or less permanent placements. In other words, both short-term and long-term inpatient treatment settings are needed.

Treatment Services

I would like to pause here to review what I've been saying. In order to serve chornic mental patients in the community we must have a variety of residential alternatives, and we must also have a variety of treatment settings. And included among those treatment settings there must be facilities for providing inpatient, outpatient, and partial hospitalization care -- and also, if possible, home care.

But we also need a network of treatment services to be delivered within these settings. Treatment settings refer to where care is provided, while treatment services refer to what is provided.

Of course, the list of possible treatment services is very extensive. It includes such interventions as social and vocational rehabilitation services, psychotherapy services, physical health services, and something that we in the United States have begun to refer to as outreach services. I can't possibly talk about all these various treatment services in detail in the short time that we have this afternoon, but I would like to make just a few points about them.

I would submit to you that the whole field of psychiatric rehabilitation in the United States has grown tremendously in the past couple of decades; it has a most impressive history and literature. Some rehabilitation programs focus primarily on increasing a patient's attention span and improving his or her communication skills; others are "work activity programs" that offer structured work opportunities for patients in supervised environments. Still other rehabilitation programs come under the heading of "transitional employment programs," and they serve as a bridge between the work activity programs and full independent employment. Many of these rehabilitation programs are very exciting in concept. They are exciting for the professionals who work in them, and they are certainly encouraging for the patients who benefit from them. They have greatly expanded opportunities for many people who are chronically mentally ill.

But we must not lose sight of the fact that other simpler kinds of rehabilitation programs are also very important for some chronic mental patients. Although we must not underestimate patients' capabilities, we must also take care not to impose undue stresses on them. Accordingly, programs with nonvocational and prevocational objectives are among the most important kinds of rehabilitation programs that we offer to people with chronic mental illnesses. Many patients simply are not able to engage in sustained work or in competitive activities, because they do not even have the minimum of social and conversational skills that would make this possible.

Another area of treatment services that the system must provide is psychotherapy. I will talk about this only very briefly, since I am not myself a clinician. However, according to some of our foremost clinical psychiatrists like Dr. H. Richard Lamb (1976), many chronic mental patients are in fact able to profit from psychotherapy. Dr. Lamb asks us not to underestimate the psychotherapeutic potential of chronically mentally ill individuals.

Now, when Dr. Lamb talks about psychotherapy for chronic mental patients, he is talking about something very different from traditional insight-oriented psychotherapy. Dr. Lamb says that psychotherapy for these individuals must focus on the "here and now." It must provide the patient with a sense of mastery that lets him or her cope with drives and symptoms and with the realities of the external environment; and so it must concern itself with such things as the meaning of symptoms, the effects of stress on a patient's career, the role and limits of medication in combating stress, and the need for the patient to understand and, if possible, to avoid anxiety-producing situations.

Before I move on to the next part of the discussion, I'd also like to mention one more kind of treatment service, and that is the category of what we in the United States are now calling "outreach" services. In my country today, for a variety of reasons that I'll be discussing tomorrow at the Voorburg Hospital in Vught, we have large numbers of chronically mentally ill people who do not readily present themselves to the psychiatric service system. They often find our formal program offerings to be forbidding and threatening. This is a relatively recent problem for us, a problem that did not trouble us in the old days of state hosital care. In those days, patients generally did not have to make very much effort in order to receive services, because they had ready access to them in the state hospital setting.

But today, in order to have access to care, patients often must take the initiative in approaching the service system. And sometimes they just cannot do that: they are too sick, too disabled, or too frightened. So we have begun to develop some interventions where the service provider is the assertive one, not the patient (Santiago, McCall-Perez and Bachrach 1985). For example, we have something called "mobile treatment teams," where trucks or vans go out to the communities and seek out the patients. They take medications, or even food, directly to those patients, instead of waiting for the patients to come to them (Cohen, Putnam and Sullivan 1984). In that way they hope to engage the patient in the service system.

These kinds of outreach programs are very critical for people who are both chronically mentally ill and homeless. And we unfortunately have growing numbers of such people living on our streets. You might say that these people represent the casualties of our new experimental approaches in treating the chronically mentally ill.

Transportation Services

Finally, I want to mention transportation services as being essential in the provision of continuity of care for chronic mental patients. Like many of the other services I've been discussing this afternoon, the need for transportation services has grown up in this era of deinstitutionalization in the United States. In the days of state hospital care, when treatment settings and residential settings were one and the same, there was obviously very little need for special transportaiton services.

But today, with residential settings and treatment settings separated -- often very widely separated -- the patient must often cover a great deal of distance before he or she can receive adequate care. And, of course, this can be quite a difficult thing for a very sick or disabled person to do.

Just getting from one place to another may be a major event in the life of a person who is chronically mentally ill.

So a comprehensive system of care must give the chronic mental patient the means for physical access to all of the programs that he or she needs. And, for that reason, transportation services -- buses or vans or automobiles -- must often be provided. This is true both in our cities, where many of the public transportation routes are very complicated, and fares may be costly; and also in our rural areas, where there is often no public transportation of any kind available. We are not fortunate enough to have your wonderful railroad system or anything that substitutes for it.

Qualitative Concerns

Now, I have just been talking about these several categories of services that chronic mental patients require if they are going to achieve continuity of care in the community. They need crisis stabilization services, residential alternatives, treatment settings, an array of treatment services, and transportation services. These are what I would call the basic *structures* that go into a comprehensive system of care for people who are chronically mentally ill.

But there are also some qualitative concerns that are just as important as -- and maybe even more important than -- these structural components. All of the service structures in the world will do very little good, if the patient does not have access to them, or if they are not relevant to the patient's unique needs So when we talk about continuity of care, we must consider not only *what* happens and *where* it happens, but also *how* it happens.

I'll give you an example of what I'm talking about. Several years ago, I was in charge of keeping records on admissions to all of the psychiatric service facilities in the county where I live. That happens to be a very sophisticated and progressive county, and it has an excellent array of service components. It offers many residential alternatives and treatment services in a variety of settings. However, my records showed that, over a time period of six months, there had been one patient who had had 17 separate and unreferred admissions to three different intpatient facilities, and no admissions at all to any outpatient facilities. That patient was, for all intents and purposes, under continuous care. But I would not say that he was, in any sense, receiving continuity of care.

One of the most important qualitative aspects of continuity of care is that services must be offered to patients over a long period of time. Many, maybe most, chronic mental patients have lifelong service needs or something approaching that. It's essential that specific episodes of care be connected to one another and be available to the patient for as long as he or she requires them.

Another qualitative consideration is that services must be individually prescribed. Patients must be enrolled in programs that are appropriate for their own specific needs. Some kinds of program interventions are exactly right for some patients. But by no stretch of the imagination can any kind of intervention always be right for all patients. So continuity of care means that we must plan for individuals one at a time. Otherwise, we get what has been called "dumping." And dumping may take place either in the hospital or in the community.

In addition to this, program offerings must be flexible. I find that far too many programs in the United States force patients to conform to some arbitrary time schedule. For example, a person may enter a halfway house, but then he or she might be expected to improve and move out in six months, when, in fact, he or she has not made sufficient progress to warrant transfer. Continuity of care must always be the companion of continuity in needs, and the flow of services must correspond to changes in patients' circumstances. With chronic mental patients, it's often not appropriate to think in terms of linear progress. The system of care must accommodate these patients, whether they progress, decompensate, or simply stay the same.

Conclusions

Time is running short, now, and I would like to summarize the points that I have been making and bring this brief talk to a conclusion. I'm pleased that we'll have plenty of time for questions afterwards.

In order for a chronic mental patient to achieve continuity in his or her care in community-oriented systems, that patient must have access to a variety of services. There must be certain essential service structures that are part of the program offerings; and, in addition, certain qualitative conditions must be fulfilled. The service structures must be available to the patient longitudinally -- over a long period of time; they must be individually prescribed; and they must be flexible.

In the United States, we sometimes refer to these qualitative considerations as "case management." Case management is the integration of services for each patient, one at a time. It implies that someone in the system of care is taking charge and seeing to it that all the little bits and pieces of the fragmented service system are falling together in some coherent way for the individual patient. It's absolutely implicit in the notion of continuity of care.

What I've attempted to do this afternoon is draw a picture for you -- a picture of the complex service needs of chronic mental patients who seek services in deinstitutionalized, community-based psychiatric service systems in the United States. These patients require special programs and a great deal of imaginative planning in order that continuity in their care may be effected. They require a wide variety of service structures. And they require that those structures be organized with due concern for such qualitative issues as permanence and flexibility.

This is not an easy task that I have been describing. In fact, I would say that it is turning out to be a very major challenge for us as we try to improve our systems of care in the United States. However, these are the things that we have been learning and that I'm happy to share with you this afternoon.

Once again, I want to thank you for your kind invitation and your superb friendliness. I'm looking forward to the next two weeks here in The Netherlands and to seeing some of your facilities for the chronically mentally ill at first hand. And, now, I am most eager to learn about your own perceptions of continuity of care.

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DEINSTITUTIONALIZATION IN THE UNITED STATES: PROMISES AND PROSPECTS*

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Thank you for your very kind invitation. I'm so happy to be here in The Netherlands and to have this opportunity to share my experiences with you. I congratulate you on this Anniversary celebration, and I very much look forward to the day's program. I'm learning so much from my visit here!

Most people in the United States today are probably prepared to acknowledge that, on the whole, deinstitutionalization has been something of a mixed blessing. There have been some wonderful opportunities in my country for chronic mental patients, in service systems that are essentially deinstitutionalized. On the other hand, there have also been some dismal things, too; and sometimes those things border on nightmares.

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I want to speak with you today about the situation that's faced by many chronic mental patients in the United States today. I see our chronically mentally ill citizens as largely having been victimized by two things. First, I see them as the victims of their own illnesses, which are often serious, debilitating, and very painful conditions. And, second, they're often victimized by service systems that have gotten into the habit of playing a lot of games with them. And, often, those games are played in the name of something called deinstitutionalization.

Now, I don't want you to get me wrong. I want to make it clear that deinstitutionalization is something that's very close to my heart. Planning services for chronic mental patients in deinstitutionalized service systems has been my major research and teaching focus for quite a number of years, now; and maybe that's why I feel so strongly that deinstitutionalization must be examined and understood. It's a very complicated business.

You may or may not be aware that last year, 1985, was something of an an anniversary year for us in the United States. It happened to be exactly 30 years since the time when we had our peak patient enrollment in our state mental hospitals. In 1955, there were about 560,000 people living as patients in our state mental hospitals. Today, just over 30 years later, the count is down to about 116,000 -- a drop of about 80 percent.

Another statistic that I'd like to mention is that we have an estimated 2,000,000 chronically mentally ill people in the United States today. That's probably a conservative estimate; it represents the midpoint in a range of estimates that our National Institute of Mental Health provides -- 1.7 to 2.4 million.

Now, if we have 2,000,000 chronically mentally ill people in the United States, and if 116,000 of them live in state mental hospitals on any given day, that accounts for only 6 percent. Where are the other 94 percent? Well, the truth is that, often, we don't know where they are -- or even who they are -- even when they desperately need our help. We can account for some of that 94 percent, but there's a very substantial portion that eludes us in the best of circumstances.

In other words, deinstitutionalization in the United States has had a rapid, and even a precipitous, history. And it's a good thing for us to ask ourselves what we've learned from deinstitutionalization: what all of our efforts have meant to and for people who are chronically mentally ill. What gains have come to these people from deinstitutionalization? And what, if anything, have they suffered as the result of 30 years of this public policy?

This is all by way of introducing the subject to you -- and pointing out to you that deinstitutionalization is a very complex phenomenon, with many different facets. Actully, you might say that it's a little bit like an elephant; when we stand up close, we can't see the whole beast. So anybody who has something to do with deinstitutionalization tends to see best -- or maybe exclusively -- that portion of it with which he or she is personally involved. But deinstitutionalization tends to look very different to the hospital-based psychiatrist from what it does to the community-based nurse who is making a home visit, or to the program evaluator who is trying to make some sense out of difficult-to-trace patient movements -- to say nothing of how it must look to the patient himself or herself, or to the patient's family.

Features of American Life

In a few moments, I'm going to share with you some of my reflections on deinstitutionalization in the United States. But before I get into the substance of my presentation, I want to take just a moment or two to acquaint you, in a very general way, with certain aspects of American culture. I hope that by doing this I'll be able to provide you with some background for interpreting my remarks about deinstitutionalization in the United States.

Dr. Alfred Freedman (1967), who is Professor of Psychiatry at the New York Medical College and a past President of the American Psychiatric Association (and someone who has devoted many years to speaking to European and Asian audiences about American psychiatry), has developed a way of characterizing what he calls "certain distinctive features of American life [that are] deeply engrained in our historical development" (p. 487) and that distinguish our country from other countries. I should like to borrow Dr. Freedman's ideas this morning to summarize the general milieu in which psychiatric services are planned and delivered in the United States

First, Dr. Freedman says, we are a pluralistic nation. No single level of government determines our institutions or our systems of care. I think that this is often very difficult for people outside of the United States to understand. We in the United States do not have a central federal policy for the care of mentally ill people. Instead, we have 50 separate state policies, and each one of them is different. And those 50 state policies may be modified, or extended, or abridged by local governments, so that service delivery varies even within the states. All of these levels of government provide some services -- sometimes. But many of our service agencies are privately owned and are not under governmental sponsorship at all. They make their own rules.

And, by no means do we have universal entitlement to general health care, or to psychiatric care, in the United States. There is no federal policy that ensure that every person who is sick will receive needed services.

Secondly, Dr. Freedman says, we are characterized by uneven development throughout the nation. Things are done very differently in different parts of the United States -- so that if you understand something about psychiatric service delivery in San Fancisco, California, that does not mean that you will understand what is going on in New York City, in Honolulu, Hawaii, or in Juneau, Alaska. This puts the American speaker at some disadvantage when he or she tries to describe psychiatric services in the United States. The best that we can do is report on general kinds of trends and orientations to patient care. But there are always many, many exceptions.

Third, Americans tend to be very pragmatic. Dr. Freedman says that we generally focus on solutions that are practical, not theoretical. We are very goal-oriented. And related to our pragmatism are several other features of American life that Dr. Freedman discusses. We tend to prefer short-term goals and so avoid long-range planning; we tend to venerate change; and we like to solve problems by adding new solutions instead of by trying to adapt old solutions to new realities. In other words, we believe in rapid change, and we expect that change to show positive results very quickly.

Now, I believe that these several cultural characteristics that I am describing may potentially be very beneficial in the care of chronic mental patients in a number of different ways. They may lead us to look for creative solutions to many of our service delivery problems. They may motivate us not to stagnate, but to look instead for new and better ways to do things. And this is apparent in some of our very imaginative planning ideas and in our so-called "model" programs for mentally ill people.

But let me assure you that Dr. Freedman does not see these characteristics of American culture as always being in the best interests of people who are mentally ill. And I agree with that. Sometimes these characteristics may really serve to complicate and limit service delivery. And I'll be talking about this situation in some detail in just a moment.

To reiterate, then, before I proceed with the rest of my presentation: our solutions to problems of psychiatric service delivery are diverse and unevenly developed throughout the United States. These solutions tend to be pragmatic and oriented toward change and short-term goals. And they tend to focus on introducing new solutions rather than on modifying old solutions to meet changing circumstances.

Some Personal Reflections

In recent years, I have been traveling a great deal throughout the United States. I have now visited about 40 of our states professionally, and I have seen at first hand how psychiatric resources for the chronically mentally ill are being developed -- or, often, as the case may be, not being developed -- in a great many places in my country.

I have observed a lot of human suffering and pain that have resulted from the movement to shift the major locus of care for chronic mental patients from institutions to the community. But, at the same time, I have also seen, in some places in the community, incredible caring and superb treatment for people who are chronically mentally ill. And these positive events are also the result of that effort to shift the major locus of care from institutions to community-based settings.

I'd like to give you just a few examples to document this paradox -- because it is truly a paradox.

During a recent visit to Rock Island, Illinois, I saw a dozen treatment refractory elderly schizophrenic women who had once been so withdrawn that they were not even discharged to the community in the days when wholesale releases were in vogue. They represented the "last wave" of deinstitutionalization: the patients for whom there had been very serious outplacement problems.

When I saw those women in Rock Island, they had been moved to a residential facility in the community -- not because they had materially improved, but rather because the state hospital in which they had lived closed down. Their new home turned out to be a very attractive large old house that had been renovated and subdivided for its new residents. Each of the women now occupied a bright, sunlit room of her own, with cheerful curtains and attractive furnishings. After the residential transfer, these women began to come out of their special nowheres, and they were now showing some minimal interest in their surroundings. Some who had been mute even lost their muteness.

I don't think that any observer could deny that something good had happened to these women and that the quality of their lives had improved materially, even though no one knew precisely why. It apparently had something to do with a simple change from an institutional to a decidedly noninstitutional environment, because their treatment regimens had not changed in any substantial way.

Another vignette:

During a visit to San Francisco, I saw a different kind of phenomenon: I saw a residential hotel that had very few amenities for its residents who were all former state mental hospital patients. Now, this hotel was hardly what anyone would refer to as an ideal residential setting. Certainly, there was none of the sunny ambience of the Rock Island house that I've just described. But it was home to the patients, and it offered some medical, psychiatric and rehabilitative services on-site. Some of the residents even had a sufficient sense of belonging in that hotel that they had decorated the walls of their rooms with pictures and birthday cards. And it was, very notably, a place where the rooms, minimal as they were, were held for the patients if they had to go back to the hospital for a few days: something that's very hard to find in most communities in the United States. On balance, I would say that living in that hotel was a positive thing for these patients.

There are a number of residential hotels like this one in San Francisco, and I learned shortly after my visit that the owner of one just like the one I'd seen apparently could not resist the rewards of what we call "urban gentrification" (Harrington 1984). He sold the building rather precipitously, and the next day there were 80 more chronically mentally ill people at risk for being homeless on the streets of San Francisco. Most of them would probably be quickly lost in a crowd of thousands of others just like themselves, because the hotel had provided the major link that many of these patients had to the system of care. And when the hotel disappeared abruptly, most of its occupants, who were very sick people by any definition, lost their connection with the psychiatric service system.

At the Massachusetts Mental Health Center in Boston, I saw some encouraging and rewarding outcomes of deinstitutionalization. I saw arrays of graded housing opportunities for people who are chronically mentally ill. Some of the homes that I visited were truly places where I should not at all mind living myself.

In the external residential programs that are associated with the Massachusetts Mental Health Center, high quality psychiatric and medical care are always available to the patients, and every patient is aggressively followed by a very competent treatment team. Residential placements are made cautiously, and there is no wholesale dumping. What's more important is that the patient is not subjected to some arbitrary requirement to progress, to move in, to move out, to be busy; but rather, he or she is placed in a setting that is appropriate for his or her changing needs -- whether this means progressing, decompensating, or simply staying the same for a while.

But during many other visits to the city of Boston, I have seen other kinds of things. I have seen hallucinating, uncared for, pathetic individuals being evicted, as they are nightly, from the only place that even resembles a home for them -- the Boston Public Library. These are the unfortunate chronically mentally ill, the ones who are not lucky enough to be enrolled in the residential programs of the Massachusetts Mental Health Center.

My travels have taught me a great deal about deinstitutionalization. In New York City, and In Los Angeles, I have visited shelters where literally hundreds of homeless mentally ill men and women, who were once institutionalized, now live: facilities that are so degrading and so inhumane -- so unspeakably horrible -- that I could only go back to my hotel room and cry after I left them.

In these, and in many other cities, I have seen how people who are released from institutions often end up starving on the streets. And I have also seen that increasing numbers of younger schizophrenic people live on the streets, too -- young adults who have never even been institutionalized, because state hospital doors are closed to them as the result of something we euphemistically call "admission diversion" policies (although the facilities to which these people might be diverted often exist only in someone's fantasy).

I have seen both young and old mentally ill people wandering and homeless, hallucinating and filthy, in places like Washington, Boston, and Seattle. But I don't want you to make any mistake about it: our large cities don't have any monopoly on this population. I have also seen them in smaller cities like Columbia, Missouri; Burlington, Vermont; and even Juneau, Alaska: the wandering mentally ill, victims of a service system that often denies their very existence.

I have seen many people who have been entirely forgotten by the system of care, the more so because they don't show a lot of promise, and they don't fit in with our fantasies of cure and rehabililtation. But I have also seen people who are diagnosed with chronic schizophrenia who, after receiving excellent psychiatric and rehabilitative care, have resumed living and now function as members of their communities. And this is one of the most gratifying things that a person can witness: the true integration of chronically mentally ill people into the fabric of their communities.

So this is where we are with deinstitutionalization in the United States today. There are tremendous variations throughout the country. In some places the signs are very good. But if you look at the country as a whole, the signs are often quite depressing.

What I'd like to do now is explore some of the subtleties of this paradoxical situation by focusing on three broad kinds of questions. How did we get where we are today in the United States? Where, in actual fact, are we? And what's down the road for chronic mental patients in the years to come?

Understanding Deinstitutionalization

There's very little doubt that deinstitutionalization is the single major policy thrust that has determined the direction of psychiatric service planning for chronic mental patients in the United States for the past two or three decades. In fact, deinstitutionalization has dominated our psychiatric service planning to such an extent, that it's probably very difficult for most Americans to imagine caring for people who have chronic mental illnesses in anything other than service systems that are essentially deinstitutionalized in concept and direction, if not in actual fact.

But the complexity of deinstituitonalization is regularly understated, not only in our popular media, but also in professional circles. Deinstitutionalization is widely regarded as the emptying, or even the closing, of our state mental hospitals -- as a matter of geography, of moving patients from one place to another place. But there is actually a great deal more to it than that. Deinstitutionalization, at least as it was originally conceived, was going to encompass two kinds of processes: both the depopulation of our state mental hospitals and the concurrent development of alternative resources for people who would otherwise have had to use those hospitals.

This is a very important, very basic, point. There was going to be a great deal more than just terminating state mental hospital programs in deinstitutionalization. New resources were also going to be developed.

In fact, I think that if you analyze the concept of deinstitutionalization -- if you try to look at its overtones and its implications -- you'll become aware that it has several different facets. There are probably three -- at least three, maybe more -- separate aspects of deinstitutionalization. Deinstituitonalizaiton is simultaneously a fact, a process, and a philosophy (Bachrach 1978) -- and I want to take a moment or two now to explore each of these aspects.

The fact of deinstitutionalization -- As a fact, deinstitutionalization may be thought of an an objective series of events -- events that are manifested in a massive shift in the locus of care for chronic mental patients. If you look at service utilization statistics in the United States as a whole, you'll see that our inpatient services -- and more specifically, our state hospital inpatient services -- have vastly decreased as a proportion of all psychiatric services. At the same time, outpatient care has increased in a most dramatic way. It is this major shift in patient care settings that gives substance to deinstitutionalization as a fact.

And deinstitutionalilzation as a fact is exactly where many understandings of that term begin -- and also, unfortunately, end.

The process of deinstitutionalization -- But, in addition to its being a fact, deinstitutionalization is also very much a process. Specifically, it is a vital process of social change -- of movement away from one orientation in patient care to another orientation that is radically different. And this process, which has now been going on for two or three decades in most parts of the United States, has all by itself affected the lives of people with chronic mental illnesses.

In other words -- and I can't stress this too strongly -- the very process of change has created its own momentum. Deinstitutionalization as a process involves all of the elements of the psychiatric service system. No agency is exempt. It's an ongoing series of accommodations and shifting boundaries. And, not surprisingly, it has generated some severe disequilibrium in the psychiatric service system -- disequilibrium that's currently reflected in a variety of problems.

So deinstitutionalization is not only a geographical fact; it's a process, too: a process that is having some secondary consequences of its own. And if we look at it simply as numbers of people who are moving from one location to another as our service utilization statistics do, then we can easily lose sight of some of the more subtle aspects of that process.

The philosophy of deinstitutionalization -- But deinstitutionalizaton is also a third thing. In addition to its being a fact and a process, it's also a philosophy -- a philosophy with its roots in post-World War II America, when a variety of civil rights protests was gaining widespread support. That was a "can-do" era, and there was a strong belief in infinite possibilities for the betterment of mankind through positive social action -- a belief that was, of course, fueled by our rapidly expanding ability to contain patients' most obvious symptoms through pharmacological advances. Patients were beginning to *seem* to be less sick than they had been in the past. They were less symptomatic. And this only reinforced the commitment of advocates, and strengthened the deinstitutionalization ideology.

But, in addition to this civil rights impetus, there was another powerful factor that also played an important role in service planning for chronic mental patients in post-war America. Community-based care was widely believed to be more economical -- more cost-effective -- than institutional care. And the ability of social reformers to ally themselves with fiscal conservatives on this issue resulted in a rare coalition of ideologies. Usually, social reformers and fiscal reformers in the United States do not have a whole lot to say to one another. But in this case they did; and this alliance was critical to the acceptance and the spread of deinstitutionalization. If community-based care was both *better* (that is, more therapeutic and more humane) and *cheaper* (that is, less costly), then why would anybody want to stop it?

Now, it's important for me to say to you that neither one of these beliefs had ever actually been tested. Nobody had ever actually *proved* that community-based care was either more humane, more therapeutic, or less expensive than state hospital care. But people *believed* these things, and that is what mattered. In fact, I think that it's safe to generalize that, in matters of public policy, belief is often more important than established fact. That certainly has been the case with deinstitutionalization in the United States.

The Realities of Service Delivery

Now, in the early years of deinstitutionalization, at the peak of our optimism and what we call "can-do" spirit in the United States, we really elected to understate both the seriousness and the chronicity that are part of chronic mental illness. We were so expansive in our optimism that we chose to think in terms of mental *health*, and effectively to ignore the existence of mental *illness*. I think that it's no accident that the major United States service initiative for mentally ill people in that era was called a "community mental health center." We did not want to think about places that are called "clinics" or "hospitals"; we did not even want to consider the issues that are associated with illness. We wanted only to concentrate on positive thinking.

Now, of course, there's nothing wrong with optimism -- up to a point. But when that optimism is unreal or unfounded, it may lead to evasion and denial and become self-defeating. And I think that this happened with our failure to focus on illness in the early years of deinstitutionalization. That lack of focus blinded us to some important realities about people who are chronically mentally ill.

One thing that we should have anticipated from the very beginning -- but we didn't -- was that there would probably be some serious practical problems associated with transferring care from a setting where patient services were centralized and easily accessed, to an essentially decentralized and fragmented community-based psychiatric service system. Either the patient would now have to seek care aggressively and put together the various bits and pices of his or her own treatment plan. Or else the community would somehow have to do that for him or her. Very probably, both would have to participate in this very complicated enterprise.

But the truth is, of course, that patients often encountered serious financial, psychological, geographical, and societal barriers that impeded their access to care. And the community often did not know how to -- or else perhaps did not really want to -- act aggressively on behalf of chronically mentally ill people. In fact, the history of community mental health in most of the United States is one in which clear preference has been given to patients who are able to take the initiative in seeking their own care. And the system seems to have had problems in serving those other patients -- the ones whose lack of motivation or lack of ingenuity keep them away from service agencies.

Another thing that we should have anticipated as deinstitutionalization was getting started -- but we didn't -- was that the community would now have to provide an extensive _array_ of services for chronic mental patients. The state mental hospital, for better or worse -- and certainly not always as we would have wanted it -- had been performing a variety of formal and informal services that would now have to be duplicated in a new setting. But in contrast to this need for comprehensiveness in the community, service planning in the early years of deinstitutionalization was usually conceptualized along only one dimension. It had a distinctly residential focus: it concentrated on where people would live -- either inside or outside of state mental hospitals. And it underestimated the need for such basic nonresidential services as psychiatric and medical care and rehabilitative opportunities.

In summary, then, we know today, from our accumulating experience with deinstitutionalization, that its architects often acted quite naively in overlooking these many different aspects of policy formulation. We know, in short, that their idealistic expectations of community-based care, while they were noble and consistent with civil rights ideology, were often not grounded in the realities of the service needs of chronic mental patients seeking care in noninstitutional settings.

So I believe that it's fair to say that, in the United States as a whole, deinstitutionalization has not proceeded as had been anticipated in the 1960s. And I believe that there are many reasons for this situation -- reasons that range from gaps and oversights in medical education and residency training, to our widespread failure in the United States to combat stigmatization of the chronically mentally ill successfully, to wide-ranging issues of funding and resource allocation. It certainly is not helpful to patients that they have no automatic entitlement to psychiatric care in my country, and that they must assertively "prove" that they are disabled in order to receive federal income subsidies.

So, as I have indicated, it appears that our idealism of the 1960s succeeded in blinding us to some of the realities of what it would mean to care for people with long-term mental ilnesses in community-based settings. And now some of those realities are coming home to us, and we often find ourselves uncertain about how to respond to them.

What are some of those realities?

Well, to begin with, the move toward community-based care has profoundly changed the nature of the population of chronic metnal patients in the United States. Never before in our history have we had so many different kinds of chronic mental patients in need of care. Some of these patients have been released from state mental hospitals after as long as two or three, or even four or five, decades in residence. But other patients, who are just as sick as the patients inside, are being denied admission to state hospitals in the first place; and some of them spend absolutely no time at all in those facilities. In fact, in some communities in the United States today, the number of chronically mentally ill people who have *never* been hospitalized probably exceeds the number who have *ever* been hospitalized.

Of those individuals who have been released from the state mental hospitals, many have been shunted to places that we really should call "mini-institutions," because they are facilities where, by most measures, the quality of patients' lives has actually deteriorated. Other released patients have shown a persistent dependency on institutional care, and they have developed patterns of repeated readmission and discharge: what we call the "revolving door." And, meanwhile, substantial numbers of patients have remained *inside* state mental hospitals. These are patients who, even in an era that idealizes the benefits of community-based care, are considered to be "poor risks" for discharge.

All of these patients differ. They differ in their functional levels, in their diagnoses, and in their treatment histories. And they all need different kinds of services.

To make matters even more complicated, many service providers, maybe for needs of their own, often recognize validity only in their own ideas about patient care and effectively deny the reality of diverse program needs for the chronically mentally ill. There has been a great deal of ego investment in specific approaches to patient care, and this has resulted in some deeply-rooted territorial feelings that serve to exacerbate service delivery problems. Professionals now fight other professionals quite openly; and, in counterdevelopments in many parts of the United States, lay people have stepped in to foster an antiprofessionalism that serves as a further barrier to needed care for many chronic mental patients (Hopkin 1985).

I believe that it is inevitable that, in this kind of service delivery climate, chaos will result; and it has. And it is not surprising that, in many instances, these tensions have had an adverse effect on patient care. In any case, they certainly have not served to ease the transition to a new style of community-based service delivery. And the chronically mentally ill, the very people who should have been the beneficiaries of the "bold new approach" John F. Kennedy enunciated in 1963 when he launched our now defunct federally directed community mental health center program, continue to suffer -- as they did before -- from inadequate attention to their most basic needs.

Positive Signs

Now, all of these horror stories that I have been describing are very frightening and very compelling. And when one sees them at first hand all over the United States as I have, it is easy to forget that they constitute only part of a picture. The wider picture shows, as I have already indicated, that many chronic mental patients have actually profited -- and that they continue to benefit -- from the new community-focused emphases in psychiatric service delivery. These patients are living happier, fuller, and more hopeful lives than chronic mental patients generally did in the era of institutional care.

And it really is not my intention to minimize those programs that have met with success. In fact, quite the contrary: the ability of our successful programs to transform the lives of some chronic mental patients has really reinforced our commitment to changing and improving the system of care. It is these successful programs that make us want to continue to try to develop new and better services for chronic mental patients in community-based settings.

Just briefly, to round out the picture, what are some positive points? Well, I would say that, on the positive side, deinstitutionalization has urged us to do something that we often forgot to do in the past. It has urged us to regard chronic mental patients as individuals who have highly specific and idiosyncratic program needs -- and not as a homogeneous lot of people to be warehoused and ignored.

Deinstitutionalization has also deomonstrated to us the tremendous importance of cultural relevance in designing programs for peopele who are chronically mentlaly ill. We now know that every community requires different kinds of programs, and that there are no universal formulas for good care.

But, most notably, I think deinstitutionalization has encouraged us to consider the potential of chronically mentally ill people, and to look for ways to enhance their living skills. We did not do a great deal of this in the days before deinstitutionalization. So deinstitutionalization has taught us that disability is a major aspect of chronic mental illness, and that we must respond to patients' functional and adaptive deficits, even as we look for ways to treeat their underlying illnesses.

These are all good things about deinstitutionalization, and they represent no small accomplishment. And we have a number of excellent programs in the United States that exemplify them. These several programs are extremely important indicators of progress, even though they may not always capture the public imagination as much as the horror stories do. And we should be proud of these outcomes of deinstitutionalization.

But, although we should be proud, we should not be complacent; because, despite the existence of some exemplary community-based programs for the care of chronic mental patients, and despite the evolution of some relevant and practicable program planning principles, the problems that are associated with providing adequate and accessible care in community-based settings continue to be both numerous and very serious. And they seem to be growing throughout the nation, not receding.

Assessing outcomes in deinstitutionalization -- So this is where we are today. Is our cup half empty, or is it half full? The answer to that question, of course, depends very much on one's perspective.

Some of my professional colleagues in the United States continue to defend the idealism of the 1960s staunchly. They resist abandoning their romantic notions about the positive benefits of deinstitutionalized care, and they make statements essentially declaring that, if we will only eliminate state mental hospitals, then we will thereby automatically eliminate chronic mental illness as well. These partisans continue to insist on the imemediate and total destruction of our remaining state mental hospitals on the assumption that there cannot possibly be anything worse than institutionalizing mentally ill people (if, in fact, they will even acknowledge that there is such a thing as mental illness; some insist that mental illness is not even "real" but is instead a sociological artifact!).

And, at the other extreme, there are other professionals in the United States who have been quick to adopt an "I told you so" attitude about deinstitutionalization. They have been quick to pick up on issues like homelessness among the chronically mentally ill and the absence of continuity in their care. And they have called for an immediate return -- they even seem to want it yesterday! -- to the old style of instituitonal care.

In short, we may say that deinstitutionalization's progress has been uneven in my country. Polarized views continue to persist, and many chronic mental patients continue to be victimized by fragmented and insensitive service systems.

Some conclusions

Now I should like to summarize what I feel are the major implications of the things that I have been saying this morning and attempt to draw some conclusions for you. We in the United States have now had some 30 years of experience to guide us in planning community-based, noninstitutional psychiatric services for chronic mental patients. And we have had mixed results in these efforts.

A major problem that is emerging for us today is that the very nature of our population of chronic mental patients is undergoing substantial change -- a problem that we should have anticipated, but, unfortunately, did not. Our old "long-stay" population of long-term institutionalized individuals is growing very much smaller, and, in their place, we have large and growing numbers of younger chronically mentally ill people, many of whom have never been institutionalized. These are the patients whom we call "new chronic" patients -- the ones who have come of age in an era of deinstitutionalization: our post-war "baby-boom" babies who have grown up.

One of our problems in reaching these new chronic patients is that our deinstitutionalization policies have often failed to provide us with the mechanics for looking ahead, for anticipating the future. Consequently, we have often planned our services unrealistically, and our concepts tend to suit older, more institutionalized and more passive, patient populations. But today's chronic patients are, as I have noted, often uninstitutionalized, and they do not respond so readily to programs for passive, institutionalized people. Quite to the contrary, they are often vocal and volatile, and sometimes very difficult to reach.

In addition, our programs for chronic mental patients often lack comprehensiveness; and they are fragmented and difficult for severely disabled people to negotiate.

There are some lessons of the past 30 years, and we are at last beginning to learn them. And we must continue to learn, as we plan for the future. I believe that we will do so; I am optimistic.

One of the things that we have learned is not to look for easy answers. We are dealing with a complex and diverse patient population that has a host of service needs. It is inappropriate for us to look for quick solutions.

But I would go further than that. It is more than just inappropriate for us to look for instant answers; I think that it is also unseemly for us to do so, to state the matter kindly. I believe that we have an ethical obligation to provide decent care to people in this era of deinstitutionalization, and we should be sophisticated enough now to understand that complex problems call for complex solutions. If we are really committed to helping chroncially mentally ill people to live better lives, and to helping them to survive in the community, then we must not minimize the complexity of the problems that are inherent in achieving those goals.

Providing community-based psychiatric services to chronic mental patients is a very complex undertaking. To think of deinstitutionalization as a simple shift in the locus of care -- to think of it only as a geographical event -- is to underestimate its tremendous complexity.

So I believe that we need to have a new understanding of deinstitutionalization today, an understanding that comes from ou 30 years of experiennce.

Deinstitutionalization, if it's going to be done correctly, is not all glamor. It is not all patients' improving, chronicity's going away, and communities' reaching out to welcome the chronically mentally ill.

It is sometimes those things, of course; and when it is, that can be very rewarding. But sometimes deinstitutionalization is less appealing things, too -- like providing care in the community to people whom we used to lock away, because we really didn't want to see them. It's seeing to it that these people are fed and clothed and provided with basic medical care. It's making certain that they have adequate psychiatric and rehabilitative interventions and dependable social supports, and even places to go for asylum when the pressures of the world become too great for them. And it's going to bat for them when other people do not wish to have them around.

That, I believe, was the promise of deinstitutionalization 30 years ago. And that is where the business of planning services must begin today.

Now, of course, it is quite possible that, once we acknowledge these circumstances, we may wish to change our collective mind and reverse the policy of deinstitutionalization. There would be some great practical difficulties in doing that; but, in any case, it is a decision that we are going to have to make. I can only hope that this decision is not forced upon us in today's political climate in the United States, before we are able to to reach our own consensus.

But, for now, I should like to leave you with a positive kind of thought. I believe that, in one very important respect, we have come a long way over the past 30 years. Today, we in the United States know how to identify both the problems we have in providing community-based psychiatric services to chronic mental patients, and the antecedents of those problems. And so we have the potential for capitalizing on our successes and confronting our difficulties in a constructive and realistic way. That puts us, potentially, a giant step ahead of where we were 30 years ago.

Now, we in the United States have finally begun to understand that there are no substitutes for honesty, caution, and restraint in service planning for chronic mental patients. And that knowledge should help us over the next 30 years, as we continue to plan new kinds of services for people with chronic mental illnesses.

Thank you once again, and I very much look forward to the remainder of today's exciting program.

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Dr. BACHRACH. Thank you, and thank you for these hearings. I am very much appreciative of them.

Occupying the wrap-up position, puts you in the place of summarizing what many other people have said exceedingly well, so what I would like to do is just to try briefly to summarize some of the policy problems that we need to confront, if we are going to turn the system of care around. Specifically, I would like to address some of the issues that accompanied deinstitutionalization, which has been our major policy thrust, for most of the United States, for the past 30 years, or so.

In fact, this is so much the case that I think it is probably very difficult for most of us to imagine planning services and systems that are anything other than deinstitutionalized in direction and in concept, if not in actual fact.

Let me say, first, that I believe this past 30 years have witnessed some very dramatic progress in the way we plan services for a schizophrenic citizen, because our concept of care and our service delivery systems are in many ways much more humane and much more sensitive than they were in the days before deinstitutionalization.

However, we have also encountered some very major difficulties in the process, and in many ways it is easier for us to talk about our successes than it is about our problems. The gains we have made have been hard won, and I think we sense sometimes that if we don't emphasize them we may lose some of those gains.

At the same time, though, I would stress that not all of our schizophrenic citizens have benefited from our deinstitutionalization efforts and several major issues have evolved. I would like to mention some of them.

A first major issue in serving schizophrenic patients, that I call to your attention, has been mentioned several times this morning, and that is the very complexity of patient population for a schizophrenic patient. In fact, never before in our history have we had so many different kinds of schizophrenic patients. This was not true in the old days, when we largely admitted patients to hospitals and they stayed there, and everybody was perceived to be roughly the same.

Today, we have people who have been in institutions for two, or three, or four decades. We have other people who are just as sick, who were never admitted to institutions. We have people who stay in institutions and people who always seem to move back and forth. This very diversity is something for which our imagination, our creativity, and even our pocketbooks, have not always been sufficient to meet the challenge.

A second major issue that I would mention, revolves around providing continuity in the care of schizophrenic patients, because the service needs of schizophrenic individuals do tend to endure over time. We tend to plan services as if they are to be delivered to single episode users of services, rather than to people who have long term often lifeterm needs.

A third major issue that I would mention, is that we also have great problems in providing comprehensive care to people who have schizophrenia. Precisely because of their illnesses and because of their disabilities, these patients tend to require a great array of services, everything from residential services to medical, psychiatric, rehabilitative, vocational, quasivocational services.

In fact, one of the things that they also frequently need is something that we can refer to as safe haven or asylum. This is part of the spectrum of services that we need to be able to provide sometimes for a short term for some patients, for other patients for a very long term. Now, I would like to emphasize that the function of asylum, need not necessarily be provided inside a place that we call an asylum.

We don't need to give these service in State mental hospitals, however, the truth of the matter is that the most comprehensive care in the past has often been afforded in State hospital settings and that we haven't often in our deinstitutionalized programs, replaced all of the services that State hospitals have served in the past.

A fourth issue revolves around patient selection and gatekeeping in deinstitutionalization. We now are beginning to understand that many efforts, that are extensively designed as deinstitutionalization programs, in fact, resist treating the most severely disabled patients. Our early attempts at community-based care simply have often failed to treat the people who are most in need, and we often have turned our attention to people who are healthy, but unhappy. This was mentioned several times this morning.

Finally, the fifth issue that I would mention and call to your attention, is that the delivery of community-based services to schizophrenic patients continues to take place against a backdrop of stigma that has been exceedingly difficult to penetrate. Neither the success is the sum of the model programs that were just mentioned in delivering community-based care, nor the active and growing concern of patient advocacy groups has succeeded in bringing about the revolution in the public thinking that, ideally, was going to accompany deinstitutionalization.

The public, and often even members of the mental health professions, continue to stigmatize people who are chronically mentally ill. The positive social sanctions that would encourage us to respond to the needs of people who are chronically disabled has simply not fallen into place.

So this is where we are today. There seems to be at least five major kinds of issues that affect service delivery for schizophrenic patients in deinstitutionalized service systems. These are concerned with the complexity of the population, with continuity and comprehensiveness of care, with gatekeeping and with stigma, and all of these issues need to be addressed and all of these problems need to be heeded, if we are going to lend support to the positive effects of deinstitutionalization and also to counteract some of the negative fallout.

Thank you.

Senator D'AMATO. Doctor, you certainly have given us a lot to think about. How do you deal with the problem that you touched on when you mentioned the word asylum, which means, to so many—it conjures the picture of the terrible institution that just literally incarcerated that person with no rehabilitation, with no effort, to all the worst images that we see flash across.

How do we deal with that, given the complexity of the schizophrenic problem, various degrees and kinds? How would you go about doing that?

Dr. BACHRACH. Well, first of all, asylum is not—we must not confuse the place with the function. I think that among people who have schizophrenic disorders, some need this kind of safe haven for a short period of time, others need it for a very long period of time. Whether it is for crisis intervention, or as a permanent kind of arrangement, it can potentially be provided in small community-based treatment facilities, if we are willing to provide them.

We know this because some of our very good programs have been able to accomplish this. At the present time, however, in many jurisdictions, the State hospital is the only place that provides this function. It need not be so, it is so in many places.

Senator D'AMATO. What happens to the community where the State hospitals for the most part have been empty. Without that kind of asylum being provided outside on a community basis, what are the results?

Dr. BACHRACH. I would hope that we would not backslide into the old systems of institutional care. I would hope that we would, at this point, try to correct what we should have done earlier, which was provide the community alternatives at the time that we started reducing the roles of State hospitals.

Senator D'AMATO. Doctor, not to unduly protract the hearing, and recognizing that you are the clean up hitter, so to speak, to you I say, don't we really have to admit that that is exactly what is taking place in most jurisdictions, that we have opened the gates and we have pushed these poor people out without, in many cases, any kind of service.

I have seen example after example where they were just pushed into whatever hotel or single room occupancy they could find, and they were, in some cases, maybe better off than others who had absolutely no places, stacked in there, no care, left to themselves, a bitter community turning upon them, those on the outside who are upset with this taking place, and to a greater or lesser extent, hasn't that really what we have done throughout this Nation?

It is the exception, rather than the rule, when you mention the community-based group that deals with these problems, where there are the facilities, I don't see them. Now, there are people like yourself and others, who are laboring in that area, but I don't see these examples where we are really dealing with those and providing them with care and alternatives, and some treatment and a sheltered environment, if they need it. I see quite the contrary.

Dr. BACHRACH. I would agree with you, Senator, that our balance sheet is not a good one. I would only submit to you that there are instances where more positive things have occurred. However, I would also say that the major problem now is not with long-term residents of institutions coming out, it is with younger people who have never even been admitted to institutions in the first place.

In many communities in the United States, they out number the institutional dischargees and they receive no care of any kind at all. That is a very major problem.

Senator D'AMATO. Therein lies the same problem, where the family then has no recourse but to cut them loose, so to speak, and does, and that adds to that problem. You find them out without resource too.

Dr. BACHRACH. There is an additional problem. The additional problem is our demography, the family of these patients are aging and they are feeling that they will not be around, and there needs to be some place that these patients can go and dependable kinds of residential and supportive services for them in the future. This is something that we have not faced up to as a nation. I think, when we started deinstitutionalization, the generation of patients who are now causing these problems, did not belong to aging parents.

Senator D'AMATO. So we have got a heck of a problem.

Dr. BACHRACH. Indeed, we do.

Senator D'AMATO. I don't think we will try to solve it right now, but I certainly appreciate your candor, because sometimes it is rather difficult to get people to come forward and say, look, as a nation, we have done a poor job here. Whether it be those we have pushed out of the institutions, or those who at least have an institution available, regardless of how terrible that may have been.

So, we have got both of those populations, not to mention their families, not to mention community at large, in this dilemma. I must confess to you, I see little progress being made in this area. It is difficult. It is very upsetting to people, some people don't even like to talk about it, and that is why I think you probably have such a great ignorance on the part of the general community. So much more in the way of education and advocacy, but education first throughout the general public.

ADDITIONAL PREPARED STATEMENTS

I want to thank you and all those witnesses for appearing today. I am advised, before I recess, to mention that we will accept testimony for the record for another week and will insert statements of Roland Kohloff and a letter from James Garner in the record.

[The information follows:]

STATEMENT OF ROLAND KOHLOFF, PRINCIPAL TIMPANIST, NEW YORK PHILHARMONIC

Honorable Sirs:

I feel qualified to speak on this subject as I am the father of a 27 year old son who is the victim of Schizophrenia. I have also had my own problems that have forced me to become hospitalized psychiatrically. I personally know the extreme and severe devastation that this illness inflicts on a family. Not only the heartbreak and anguish of seeing your own child turn from a healthy and highly promising individual into a totally disfunctional one...But also the catastrophic effect, financially, it can have upon a family. We have run up billings of around $120,000. which we are unable to pay. However I know of familys with more than double that amount owed, This illness nearly caused the total destruction of our family.

Steven was, to all appearances, a perfectly healthy and normal young man up until the age of 18. He was an outstanding scholar at his private high school who, for most of his years there, was in the top 20% of his class.

He was also an outstanding athlete. Upon approaching one holiday season, wher he seemed to feeling very low, my wife and I sent him to a professionally run baseball camp that was being held at the Philadelphia "Phillies" training base in Clearwater, Florida. There he was told, by more than one Major Leauger, that he had the goods to make it to the Big Leagues.

In the middle of his first year of college, at FORDHAM UNIVERSITY in N.Y., the illness manifested. He became hospitalized and has since been hospitalized some 19 or 20 times currently residing in a N. Y. State Hospital in our county

Gentlemen, I speak not only on behalf of my son but for all the many thousands of people comparably institutionalized. Many of these have been abandoned. Many others have been so tortured by the illness they have taken their lives. THIS ILLNESS FOR THEM WAS WORSE THAN DEATH.

It was shocking for me to learn that 25% of all the hospital beds in our count are occupied by people with Mental Illness. Yet our Government has only been allocating funds to find a cause and cure as they are to finding the cause of tooth decay! I submit to you all that this is a national disgrace. And one we must correct.

We must wage a war on Mental Illness. Dr. Torrey and Dr. Frazier may be the best generals in the world but they need troops and ammunition. There are many of us out there willing to be troops. But we need the ammunition from you.

I have to tell you that there is a momentum gathering, across our country, you must be made aware of. My family has made a documentary, produced by MEDSTAR COMMUNICATIONS of Allentown, Pennsylvania that will be shown on some 46 outlets in the country. It has already been shown in the Washington, D.C. area. This 12 minute segment has now been deemed so powerful that we have been approached to make a full length feature film from it.

I am delighted to know that the Senate is taking an actice interest in the plight of the Mentally Ill. I implore you to do what you can and as much as you can to help these unfortunates who have been turned into human cattle and have NO LIVES at present with VERY ISOLATED HOPE the way things now are.

In closing I bring you a personal message from my friends:

Angela Lansbury

Zubin Mehta, Music Director of the New York Philharmonic

and

Leonard Bernstein.

All of them are on the committee of; "Friends of the National Alliance for The Mentally Ill." Their message is simply but fervently:

"Please help us!"

Thank you.

Letter From James Garner, Garner-Duchow Productions

20 November 1986

The Honorable Senator Lowell Weicker, Jr.
Chairman of the Committee on Appropriations
United States Senate
Washington, D.C. 20510

Dear Senator Weicker and Honorable Members of the Committee on Appropriations:

I am writing today to strongly urge you to appropriate funds for research on schizophrenia and related community awareness programs.

I am no expert on schizophrenia. Fortunately, others are testifying before you today who can offer sophisticated perspectives from the medical and psychological professions about this tragic brain disease. I am one of those who, until recently, has had little contact with schizophrenia and has been ignorant of its tremendous prevalence in our society. My awareness of the disease really began with my involvement in a film, "Promise," which will air on television next month. "Promise" portrays the trials and desperation of a man attempting to come to terms with his schizophrenic brother. The role made a tremendous impact on me not only because I got a taste of the living hell that schizophrenics face each day but because I now see and am ashamed of how society has turned its back on people who did not choose their lot, who did not want to be victims of this brain affliction. When we should be doing whatever we can to treat this disease and relieve the suffering of the one to two million schizophrenics in the United States, we have instead made these victims carry shame and guilt for an illness that most certainly is not their fault.

I am amazed, as I am sure you are, by the staggering costs -- treatment costs and productivity losses -- sustained by society because of this disease. Some authorities estimate the annual cost to be $48 billion. In just one year (and every year!) our society spends twice the amount that it has taken to purchase a fleet of B-1 bombers over twenty years. And while the incidence of schizophrenia is substantially higher than other horrible diseases like multiple sclerosis, diabetes, and muscular dystrophy, research and treatment programs related to schizophrenia are the least funded of these.

In my mind, this is a terrible injustice that we absolutely must correct. It is our responsibility to make society aware of this illness, of the fact that it is an illness and not the product of bad family upbringing and other myths. We have the resources to learn more about this disease and hopefully we will one day be effective at combating it. What we need now is the commitment and courage to finally face schizophrenia instead of hiding it away in our homes as we have done for so many years.

I urge you to carefully consider the requests being made today and to respond favorably to our appeals. What has been a real national health tragedy can and should be corrected now.

Thank you for your consideration.

Sincerely,

James Garner

James Garner

Letter From Irving Feller, M.D., University of Michigan Burn Center

November 19, 1986

Honorable Lowell Weicker, Jr.
United States Senate
303 Hart Senate Office Building
Washington, DC 20510

Dear Senator Weicker:

Enclosed please find my support for Mrs. Scott's testimony scheduled for tomorrow November 20, 1986. I believe that the successful program system we initiated in 1957 can be an effective model for resolving the problem of Schizophrenia.

Sincerely,

Irving Feller

Irving Feller, M.D.

STATEMENT OF IRVING FELLER

I have read the testimony of Trish Van Devere Scott and am deeply impressed by the urgent plea to improve the response to the needs of the schizophrenic patient. This brief report outlines how another medical problem; the burn problem was addressed. Trish Van Devere Scott, as a member of the Board of Directors of the National Institute for Burn Medicine, became aware of the methodology used to better understand the burned patient's multifaceted problems.

In 1959, only four of the 6000 acute care hospitals in the United States had specialized burn care facilities. There was a general lack of professional and public attention resulting in a high incidence, mortality, morbidity, disfigurement, and dysfunction. Rehabilitation for these patients was almost non-existent. Although the second World War had added to the experience, knowledge on burn care was sketchy. There was no accumulated body of information, no organized training, and very little research. At that time, we realized that it was necessary to define the problems and formulate corrective action to reduce or resolve each problem as it became apparent. There are four categories of response:

1. Programs for better organization and management of patient care were established. This required a definition of the levels of care that existed, and what was needed in terms of personnel, resources and facilities to provide this care (see Appendix A, B, C)

2. Data was needed to better identify the cause, the incidence, the treatment, and the outcome. No one burn care facility had enough patients to statistically analyze the

complex burn problem. The National Burn Information Exchange (NBIE), a national, voluntary physicians registry, was established in 1964 at the University of Michigan to collect data from as many burn care facilities that would participate. The NBIE, continues to define the problems on a national basis and now has 97,856 case records on file from 130 hospitals. Fifty hospitals contribute 6,000 new cases each year. Analyses, made continually, are relayed to participants, government, and industry (see Appendices D, E).

3. The International Bibliography on Burns was established at the University of Michigan in 1965 to collect and classify the world literature on the burn problem and related subjects. This collection facilitates the immediate dissemination of the literature to professional for care, research, teaching and prevention. We now have 41,419 publications on file, classified by topic, and updated yearly. Professionals working in the field have access to this literature in minutes, rather than taking hours or days to read about specific topics (see Appendix F).

4. A system was needed to make the medical profession and public aware of the problem and help them work together toward a solution.

- in 1959, National Burn Seminars were begun as a joint program between the University of Michigan and the Brooke Army Burn Center in an attempt to increase professional interest in burn medicine.

Nine physicians attended the first meeting. At each successive meeting, more surgeons became involved, so that by 1968, 200 attended the meeting. At that time, the American Burn Association was formed which now has 2,000 members representing all professions who work in the field, i.e., surgeons, nurses, physical and occupational therapists , social workers, school teachers and many others. Now 150 hospitals in the USA claim some level of specialized burn care.

-in 1968, The National Institute for Burn Medicine (NIBM) was founded in Ann Arbor, Michigan to function as a not-for-profit, health-care-support, organization, similar to the American Cancer Society and other credible organizations. The National Institute for Burn Medicine publishes professional educational materials, provides educational programs, supports research, and publishes and disseminates prevention materials. (see Appendices G, H, I, J, K)

These are a few of the activities that, twenty-five years later, have resulted in burn patients getting better care, improved survival, improving rehabilitation, and more public awareness. Most importantly, medical professional are now being trained to provide better care through research and teaching. Problems remain to be resolved. The dedicated and trained personnel, special facilities, and the methodologies for their resolution are in place and, with the proper support, we have hope that they will continue to be effective.

It is my belief that the programmatic approach to improving the burned patient care would be helpful in other areas of medicine, such as resolving the problem of Schizophrenia. We at the University of Michigan, would be pleased to assist in this endeavor.

Schizophrenia

Feller Support of Vandevere Testimony

List of Appendices

1. A. Reprint: Planning and Organization of a Regionalized Burn Care System; Prais, Feller, James.

B. Reprint: "Burn Center Dedication at University of Michigan" in Profiles, Fall, 1986, Kellogg Foundation.

C. Program: The Burn Center for the University of Michigan Burn Center Dedication, September 17, 1986.

2. D. Reprint: The Use of a National Burn Registry to Evaluate and Improve Patient Care.

E. Reprint: Improvements in Care 1965-1979.

3. F. Book: 1985 Supplement - International Bibliography on Burns.

4. G. Brochure: NIBM

H. Reprint: A Decade of Progress in Burn Medicine

I. Reprint: The WK Kellogg Great Lakes Regional Burn Care Demonstration Project

J. Brochure: Burn Care Educational Materials

K. Pamphlet: 50% of All Burns Can Be Prevented

STATEMENT OF THE AMERICAN COLLEGE OF NEUROPSYCHOPHARMACOLOGY

Mr. Chairman, I am Dr. E.H. Uhlenhuth, Professor of Psychiatry at the University of New Mexico.

On behalf of the American College of Neuropsychopharmacology (ACNP), I appreciate this opportunity to submit a statement for the record in relation to the hearing conducted by the Appropriations Subcommittee on Labor, Health and Human Services and Education on "Schizophrenia: The Plight and the Promise" on November 20, 1986.

ACNP is an organization of some 430 scientists from all relevant disciplines concerned about the biology of the central nervous system, and its relationship to the causes and treatment of mental and addictive disorders. Many ACNP members are directly involved in research relating to major mental illnesses, including schizophrenia, and we very much appreciate your and the Subcommittee's interest in the subject of today's hearing.

In fact, over the summer, as ACNP became aware of Congressional interest in the status of schizophrenia research, we thought we could be of assistance in providing, from an independent scientific point of view, an overview of the status and opportunities in the field. As a result, ACNP's governing Council approved the formation of an ad hoc committee on schizophrenia research charged with developing a working paper to make recommendations on how an initiative on schizophrenia research could be structured in a scientifically sound manner. Participating in this ad hoc committee are four distinguished scientists: Dr. Arnold Friedhoff, Professor of Psychiatry, NYU School of Medicine and Director of Millhauser Laboratories, Chair; Dr. Gerald Klerman, former Administrator of ADAMHA, Professor of Psychiatry, Cornell University Medical College; Dr. John Kane, Professor of Psychiatric Research, Hillside Hospital, Glen Oaks, N.Y.; and Dr. John Talbot, Professor and Chairman, Department of Psychiatry, University of Maryland.

I am pleased to say that the preparation of this report is moving along well, with a draft expected in December for review by ACNP's Council. It is very much our desire to present the results of this report to you and other members of the Subcommittee and the Congress, to be of assistance in guiding your thinking as you begin the next cycle of budget preparation and appropriations early next year. I believe it will directly address many of the questions that you and members of the Subcommittee have indicated are of interest to you.

Second, ACNP is heartened by the activities of the organizations representing patients and families, several of which are represented at this hearing. The message that many of them have conveyed is one with which ACNP agrees -- key to making progress with respect to understanding, treating and ultimately curing these illnesses is research, which can only be accomplished through adequate funding.

Indeed, next month, during the annual ACNP Scientific Meeting, which will also be the occasion of ACNP's 25th anniversary, ACNP will join with the National Alliance for the Mentally Ill, the National Mental Health Association, the National Federation of Parents for Drug Free Youth, the National Council on Alcoholism, and the National Depressive and Manic Depressive Association to announce a partnership, a community of interest, to seek additional research funding. The partnership, entitled "A New Partnership for Hope and Progress: Advocacy for Research on Brain and Behavior," will be a first in terms of scientific organizations and advocacy organizations in the field of mental health joining hands for common goals.

But, with respect to how any new initiative will be structured, a note of caution needs to be sounded. There are not likely to be simple answers to the questions that preoccupy us. It is all too easy to believe that a magic solution will result from shifting jurisdictions from one institute to another, or from subscribing to a simple theory about the etiology of a complex illness like schizophrenia. It is likely that the expertise and experience of all the disciplines that have been working in this area will continue to be needed to make contributions to the progress we all desire to see.

On behalf of ACNP, I wish to express my appreciation to you and the Subcommittee for your interest in schizophrenia and for the opportunity to outline to you the special efforts that ACNP is making -- the soon-to-be completed report on opportunities in schizophrenia research, and the soon-to-be announced partnership between ACNP and several mental health advocacy organizations -- in an effort to contribute to the acceleration of progress in understanding schizophrenia. ACNP hopes for an opportunity to work with the Subcommittee as it continues its consideration of this issue, and would be honored to serve as a resource for dealing with the many unanswered questions relating to schizophrenia.

LETTER FROM THELMA I. HAYES, CHAIR, PUBLIC AWARENESS COMMITTEE, CALIFORNIA ALLIANCE FOR THE MENTALLY ILL

P. O. Box 1366
Carlsbad, CA 92008
619/434-1054
November 11, 1986

Senator Lowell P. Weicker
113 Hart Senate Office Building
Washington, D. C. 20510

Attn: Terry Muilenberg

Dear Senator Weicker:

Will you kindly submit the enclosed article, "Schizophrenia Research: A Forty-Year Travesty," as written testimony for your hearing on November 20, 1986?

Also, I am wondering if questions could be asked of Secretary Bowen, Dr. Trachtenberg and Dr. Frazier, if they are present, relating to the information which Congressman Packard sent to his constituents in response to letters he received during Mental Illness Awareness Week. He wrote:

"Congress, in its authorization for the National Institute of Mental Health, does not specify the amount NIMH must spend on various research areas. The administration's budget outline notes the funding request for research, but NIMH board members decide as a panel what should be spent on specific projects. During the current fiscal year, NIMH spent $22 million on Schizophrenia investigation out of a total research budget of $200 million."

If it is posssible, these are the questions:

Why is so little devoted to schizophrenia research considering the enormous human costs and the expense to the U. S. taxpayers?

On what research is the remaining $178 million spent?

Of the $200 million, how much is actually devoted to research on brain diseases and disorders, including depression and manic depression?

Thank you so much for your efforts on behalf of the mentally ill.

Sincerely yours,

Thelma I. Hayes

Thelma I. Hayes, Chair
Public Awareness Committee

SCHIZOPHRENIA RESEARCH: A FORTY-YEAR TRAVESTY

by
Thomas H. Hayes, Ph.D., M.D.
Thelma I. Hayes
Les Campbell

INTRODUCTION

"Schizophrenia Research: A Forty-year Travesty" is excerpted from THE TRUTH ABOUT SCHIZOPHRENIA AND OTHER BRAIN DISEASES -- a newspaper series currently being published.

Dr. Thomas Hayes is the former director of the Department of Drugs of the American Medical Association. He serves as the representative of the California Alliance for the Mentally Ill on the first research advisory committee to the Department of Mental Health in the state of California.

Thelma I. Hayes chairs the Public Awareness Committee for the California Alliance for the Mentally Ill.

Les Campbell is a member of the committee, and is a founder of the Copper Hill Center for Living and Learning in Vista, California -- a residential supported-work program for the chronically mentally ill.

SCHIZOPHRENIA RESEARCH
A FORTY-YEAR TRAVESTY

The year is B.C. 4,000. An endless succession of babies in baskets are floating helplessly on a river above a raging cataract. The down-river tribesmen are plucking them out and caring for them at great cost to their village economy. But no one is going up-river to find out who's putting them in, or why.

For centuries, a succession of brain-diseased people have been cared for by society and the staggering costs continue to mount. Although the name, "schizophrenia" was first coined near the beginning of the 20th century, it is not a modern-day plague.

Only in the last three decades, because of the closing of state mental-hospitals, has the general public become aware of the problem. Shamefully, and almost unbelievably, modern-day efforts to find cause or cure has been the same as for the ancients: Neither have vigorously sought the origin of their burden. And as a result there are about two million innocent, incapacitated victims of schizophrenia this year in the United States alone.

Sharon is one of them. She was graduated from high school with honors last June. Her father, a political science teacher at a nearby university, was looking forward to her being on campus. Sharon's onset was sudden. She began to say things like, "My heart has stopped. I'm growing into a giant. Can't you hear what I'm thinking?" Then, gradually, she became detached from the real world.

Now, almost a year later, when Sharon's parents search her vacant eyes, they wonder if they will ever be able to pick up the pieces of their shattered dreams. Numbed to the pain of their loss, they demand answers to questions they never had before: Why, after all these centuries, has science not found a single cause or cure? What is the cost of schizophrenia to tax-payers? How much is allocated to care and treatment? How much for research? The answers are shocking.

Cost estimates of the disease range from $20 billion annually, as calculated by the National Institute of Mental Health (NIMH), to $48 billion reported by the Institute of Medicine of the National Academy of Sciences. California's projected budget for next fiscal year is just under $1 billion. Guess how much is going up-river for research -- less than one tenth of one percent.

"Given the cost to society of mental illness, it's unbelievable how little investment in research there is. And this at a time when the biomedical opportunities are so exciting." -- Richard T. Greer, Director of Government Relations, National Alliance for the Mentally Ill.

For each victim of AIDS, more than $10,000 for research are allocated. Only $14 per patient are being spent to unlock the mysteries of schizophrenia. AIDS is a horrible disease, and fatal to its victims in a very short time, but cause and preventive measures have been well documented. Schizophrenia, on the other hand -- for most, means 40 to 60 years of fear, anxiety, and isolation without hope of cure. For schizophrenia, there are no preventive measures known to date.

The history of the National Institute of Mental Health suggests failure in the truest sense of the word. Harry S. Truman founded NIMH 40 years ago because of the great number rejected for service during WW-II due to psychiatric disorders. It was to be a research institute. But since there were only about 3,000 psychiatrists practicing in the

United States in 1946 a training function was added at the last minute.

How have those educated with public funds over the past four decades served the severely mentally ill? The history of NIMH answers the question. "A survey of private psychiatrists in 1975 found that only 11 percent of the patients that psychiatrists see in private practice had schizophrenia." --E. Fuller Torrey, M.D., Surviving Schizophrenia: A Family Manual. Professionals who devote their careers to severe mental illness are rare exceptions.

NIMH money has not provided treatment and care for the seriously and chronically mentally ill. A look at how its budget is allocated tells us why. The last forty years have seen the NIMH yearly budget grow slowly and like a dry sponge absorb everything that can remotely be tied to mental health -- the stress of poverty, malnutrition, drug abuse, alcoholism, racism, AIDS, terrorism, and even the effects of earthquakes on the nervous system. This left inadequate funding for research on diseases of the brain. The original purpose for the Institute -- research into the cause and cure of schizophrenia and other brain diseases -- has been almost forgotten.

Nothing short of declaring war on schizophrenia will turn this around. There must be strong advocates. "...for if the trumpet give an uncertain sound, who shall prepare himself to the battle?"

Does Dr. Shervert Frazier, Director of NIMH, want to be the leader? Does he have a war plan to conquer schizophrenia? Does he have the price tag figured out? Has he done sufficient homework to demand of Congress appropriations to finish the job? Does NIMH have the courage to deliver the message to Congress and show that it makes good economic sense?

Why is it important to have forceful leadership? Because two to three million people in this country still suffer from schizophrenia disorders; 100,000 new cases occur each year; 75,000 of them are hospitalized for treatment of the illness on any given day; about twenty-five percent of the nation's street people suffer from schizophrenia; and one student out of every 100 of a high school graduating class will contract schizophrenia before his or her 25th birthday regardless of religion, race, political party, or social standing.

Frank is one of them. Forty years ago, when most of his friends were in college, he tried to kill himself. When he is lucid he wonders why he was rescued. But most of the time he's a street-corner preacher of his delusions. He wanders our city's back alleys and eats left-overs from our garbage cans.

How many more Sharons and Franks will float aimlessly on their down-river course before NIMH seeks the origin of their suffering and this heavy community burden?

As Director, Dr. Shervert Frazier is credited with raising the status of schizophrenia research within NIMH, and with asking for a "Manhattan-Project" effort, similar to the urgency pressed upon scientists for developing the atom bomb and ending World War II. But what has happened to Frazier's call to conquer the enemy that lays waste to the lives of one in every 100 innocent youth?

Frazier recently spoke of the $138 million NIMH research budget. But only $18.4 million were targeted for studies of schizophrenia. "...an inadequate proportion for a disease of this magnitude," he admitted.

Frazier knows that it costs nearly $500 a day for a mental hospital bed, $40 to $65 a day for minimal outpatient care, and that less than 3 cents a day are spent per patient to unlock the mysteries of schizophrenia. What are his plans for correcting this inadequacy which was passed on to him by the immediate past director of NIMH, Dr. Herbert Pardes?

Pardes is now professor and chair of psychiatry at the Columbia University College of Physicians and Surgeons. In his response to the four-part series on schizophrenia (New York Times, March 16-19, '86), Pardes writes, "Federal policy makers must recognize that financial commitment on a national level is vital if the grim and baffling prospects for schizophrenia are going to change."

Why couldn't he, as a "federal policy maker", bring this commitment to his own NIMH tenure? What advice can he now offer Frazier to help him lead a crusade against these "grim and baffling prospects" to find cause and cure of major brain diseases -- the purpose for which NIMH was organized and funded forty years ago?

Frazier did cite, as an example of progress, Julius Axelrod, NIMH Nobel prize winner, for findings on mechanisms of neurotransmitters. But the role of these has been known since 1920. Theories existed, but tools to test them did not: Now they do.

He lauded NIMH scientists for making "brain imaging" possible. It lead to Positron Emission Tomography and made possible the taking of pictures of the functioning, active brain.

Other brain-scan tools are equally under-utilized: Computerized Axial Tomography, Magnetic Resonance Imagery, and Brain Electrical Activity Mapping. Why are they not more vigorously used by scientists to search for structural changes in the brains of schizophrenics? The answer is obvious: Money. And because of scant funding, those with schizophrenia continue to get short shrift.

Dolores is one of them: She became ill a year ago. Her father, like most parents, has gone to the end of his financial resources to rescue a loved one. Last year, for example, he paid $860 for a single brain scan.

Recently, Dolores' father discussed this inadequacy of research funding with Dr. David Shore of NIMH. Shore tried to sell the father on the idea that a fine balance exists between the availability of higher qualified grant seekers and the present funding level. Five years earlier, Dr.

Pardes expressed this same attitude in a letter to the president of California's first state organization of families of the mentally disabled. Dr. Samual Keith, Schizophrenia Research Branch at NIMH, wrote for him that NIMH probably couldn't use an extra $50 million because they had no unfunded high-quality research proposals. Nor were there enough qualified researchers interested in mental health.

This attitude did not prevail in the recent campaign to find a cure for AIDS. Research allocations for AIDS were increased to $100 million in 1985-86, suggesting that grant writers are keenly aware of dollars available. They don't waste time on areas insufficiently funded: They go where the money is.

Schizophrenia is a world-wide problem. The cause(s) and the cure(s) must be identified. And, with that same priority, adequate means of caring for those afflicted must be improved. Surely, if we can afford to spend billions on such an ill-conceived idea as the Bradley Army tank (Time Magazine, March 7, '83 and February 27, '84), we can risk a few hundred million to unlock the dungeon that is schizophrenia?

Dolores' father feels that NIMH physicians need to take a look at the real world. No longer are victims' relatives buying the status quo. They're demanding answers to: What is being done to reduce the terrible side effects of medication? How many schizophrenics have access to brain-scan? How many are classified and tracked by brain imaging? How many facilities study a viral cause to the disease? How many study gene abnormalities that define schizophrenia? How many study schizophrenia brain chemistry?

Is it possible that research of brain disorders might be more appropriately placed in the hands of NIH's National Institute of Neurological and Communicative Disorders and Stroke?

Without intelligent answers, parents see the record and attitude of NIMH as a national disgrace. When other citizens, those not burdened by this horrible disease, realize what it is costing them in tax dollars, they will resent it, too!

* * * * * *

SOME THINGS YOU CAN DO TO HELP:

I- Send your Congressman and Senators a copy of this article and ask them to take the lead in the search to find the causes, the cures of these brain diseases and to provide adequate means of caring for those afflicted.

II- Make copies of this excerpt for friends and other AMI members. Ask them to write their Congressman and Senators stating their own desires for funding of schizophrenia and other brain disorders research.

III- You can help educate the general public about mental illness by getting the series, THE TRUTH ABOUT SCHIZOPHRENIA AND OTHER BRAIN DISEASES published in your local newspapers. For copies, write to:

National Alliance for the
Mentally Ill (NAMI)
1901 North Fort Myers Road, #500
Arlington, VA 22209

CONCLUSION OF HEARING

Senator D'AMATO. If there is nothing further to come before the subcommittee, the subcommittee will stand in recess.

[Whereupon, at 12:40 p.m., Thursday, November 20, the hearing was concluded and the subcommittee was recessed, to reconvene at the call of the Chair.]

O